Self-awareness following a brain injury in childhood:

a developmental perspective

by

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(Appendix 1)

Abstract

Impaired self-awareness is a common consequence following a brain injury in adults, particularly when the brain injury is moderate or severe. Impaired self-awareness affects engagement in rehabilitation and results in poor long term functional outcomes. There is a paucity of literature regarding self-awareness following a brain injury in childhood. Consequently, little is known about the differences between children and adults in the domain of self-awareness following brain injury.

Children and young people are at different stages of development when their injury occurs and this study investigates the impact of the brain injury on the development of self-awareness. The aim of this research study is to gather quantitative and qualitative longitudinal data from children and young people who have experienced a moderate to severe traumatic brain injury in order to understand their level of self-awareness.

This study used a longitudinal multiple case study design with mixed methodology. Fifteen children and young people with a moderate/severe traumatic brain injury were recruited and data were collected from the children and young people, their parents and their teacher over an eighteen month period

The results show that children and young people have an interruption to the development of self-awareness following a traumatic brain injury. Impaired self-awareness is not chronic in this group and they continue to make developmental gains in time.

This study adds to our understanding of the interruption of self-awareness development following a brain injury in childhood. Occupational therapists have a particular role to play while engaging with children and young people in the everyday context of their lives, which is supportive of greater self-awareness. As children and young people become more able to assess their own performance,

they may be in a better position to set realistic rehabilitation goals. Implications for future clinical and academic children's neurorehabilitation are outlined.

Abbreviations

OT	Occupational therapy
SLT	Speech and language therapist
SENCO	Special needs coordinator
ICF	International Classification of Function, Disability and Health
ICF-CY	International Classification of Function, Disability and Health
TBI	Traumatic brain injury
SUI	Self-Understanding Interview
KIC	Knowledge Interview for Children
ADL	Activities of daily living
GCS	Glasgow Coma Score
PTA	Post traumatic amnesia
#	Fracture
MRI	Magnetic Resonance Imaging (scan)
CT	Computerised Tomography (scan)
SES	Socioeconomic status
SAH	Subarachnoid hemorrhage
SDH	Subdural hemorrhage
ICP	Intracranial pressure

1 Chapter 1: Introduction

1.1 Rationale

This thesis presents a research study of children and young people who have sustained a brain injury and investigates the impact of the injury on self-awareness. The intention is to place the study within the context of interrupted child development. This premise arises as a challenge to the common practice of translating the findings of adult research studies to the children and young people in our care. In the last three decades we have seen little of this focus and two authors make crucial albeit passing comments on the subject:

> "Children are not short adults" (Ylvisaker, 1998b, p. 6)

> "Children first and head-injured second" (Oddy, 1993, p. 314)

The study presented here will take these passing comments very seriously. Rather than adopting the principles established in the adult literature, this study will be influenced by a recent work that had a different perspective (Tonks et al., 2007a). These authors examined the consequences of a brain injury in childhood alongside the developmental processes of emotional and social communication, while still acknowledging the adult literature. This integrated approach was promoted in an earlier theoretical article that also combined developmental concepts and adult research regarding the role of the frontal lobes (Stuss and Anderson, 2004). Although a full review of the literature will follow in Chapters 2 and 3, these opening comments outline the early influences on the direction of the current

research. In particular, the research will focus on the consequences of an interruption to typical development of self-awareness following a brain injury.

Impaired self-awareness is commonly cited as a sequela of brain injury. It is purported to have a negative impact on engagement in rehabilitation and can subsequently lead to poor long term functional outcomes. The scope of this study is to investigate the nature of self-awareness following a brain injury in childhood from a perspective of child development.

The findings of this research will have an influence on clinical practice while also suggesting the course of further research. Future studies can use the findings to explore whether some of the same relationships influence engagement in paediatric rehabilitation and long term functional outcomes for children following a brain injury.

1.2 Aim of the thesis

The overall aim of the thesis is:

> To gather quantitative and qualitative longitudinal data from children and young people who have experienced a moderate to severe traumatic brain injury in order to understand their level of self-awareness.

In order to achieve this goal the research objectives are:

1. Explore the profile of self-awareness following moderate to severe TBI in childhood
2. Compare the profile to typically developing children as reported in the literature

3. Explore the profile of the ongoing development of self-awareness following TBI in childhood
4. Compare the ongoing profile to typically developing children as reported in the literature

1.3 Thesis structure

This thesis is structured into 10 chapters. Following this thesis introduction, Chapter 2 describes in detail all of the background concepts and their relation to this thesis. The literature relating to child development, brain injury and occupational therapy will be synthesised and presented. Chapter 3 is the formal literature review for this study. The detail is primarily taken from a published paper on the literature review (Wales et al., 2013). Few articles are sourced from the formal literature review, and this chapter will conclude with the research aims and objectives. Chapter 4 contains the scientific methodology of the research study that will form the rest of this thesis. The study has a longitudinal case study design using mixed methods. Fifteen children and young people are recruited to this research study and Chapter 5 gives an overview of each of their cases. These case descriptions primarily outline the injury and post-injury presentation for each of the children and young people.

Chapters 6 to 9 present a synthesis of the results from the data collection. Initially Chapter 6 will present the individual discrepancy results. The results include a comparison between self-report and that of significant others in addition to a comparison to that expected of typically developing children. Chapter 7 will

outline the thematic data and the results from the interview data. Key themes emerge that are closely related to typical children and additional themes relating to brain injury will also be reported. Chapter 8 contains the data from the ten cases that remained in the study for more than one year and explores their pattern of change over time. Chapter 9 presents a synthesis of all of these results and the cross-case analysis. There are patterns in the data across cases and across domains in addition to across time.

Chapter 10 will be a discussion of the main trends in the data across time and across cases with acknowledgment of the study limitations, the ethical issues and the implications for further research. The results will be presented and discussed in relation to the adult literature, child development, rehabilitation and occupational therapy practice. Theoretical and clinical implications of the results are presented.

A final conclusion will spotlight the main findings of the study and consider their contribution to the future of rehabilitation for children following a traumatic brain injury.

2 Chapter 2: Background

2.1 Chapter overview

This chapter will introduce and describe the key concepts related to the topic of self-awareness following a brain injury in childhood. While the main focus of this thesis is the interruption to typical development, it is necessary to set the context by introducing definitions from both adult brain injury and child development at the outset. Following the definitions, the next sections of the chapter will describe the typical development of self-awareness in childhood.

Developmental theories will be used to illustrate the developmental trajectory with reference to philosophical context. The development and maturation of the brain is then outlined prior to introducing a brain injury as one of the possible causes of an interruption to typical development of self-awareness. The chapter will describe recovery and rehabilitation following a brain injury with a particular emphasis on the role of the occupational therapist. The final section will outline the relationship between occupational therapy and self-awareness.

2.2 Definitions

From the adult literature we learned that impaired self-awareness is a common sequela of a brain injury, particularly a moderate or severe brain injury (Hart et al., 2009). It is purported to have a negative effect on the person's ability to engage in the rehabilitation process and unfortunately this can lead to poor long-term functional outcomes (Livengood et al., 2010, Dirette, 2008). The terms insight and awareness are often used interchangeably in clinical practice. Furthermore, they

are often used to describe a general adjustment of a person to their new circumstances and reduced ability to recognise the problems experienced as a result of their brain injury. In broad terms, awareness is defined in one key text as "knowledge of one's illness or deficits." (Toglia and Kirk, 2000, p.57). However, this broad definition does not indicate the behavioural consequences of such a deficit.

One key author describes an "experience of normality despite brain damage, coupled with the *simultaneous perception* of an altered sense of self" (Prigatano, 1991, p.112). With this clinical definition the reader gets an indication of the tension that exists for the patient who has knowledge of self prior to their injury and is struggling to accept the limitations of the new self. There is a temporal aspect to this definition that references the past and the present. This temporal aspect is given more weight in a more recent definition that states "Self awareness is the knowledge and awareness people hold about themselves as individuals with a past, a present and a future" (Crispin, 2006). Crispin is amongst authors from a developmental tradition who are influenced by the 19th century philosopher William James and accept the two-fold development of self from a cognitive and a social/environmental perspective (James, 1890). A further definition is proposed in the context of measurement. In considering the measurement of the construct of self-awareness of deficits, a discrepancy value is promoted. Self-awareness is intact if:

> "there is no discrepancy between a client's observed activity limitations and the experienced and self-described activity limitations after the performance of specific ADL tasks" (Kottorp and Petersson, 2011, p.220).

This means of measuring self-awareness of deficits is based within the activity setting (ADL = activities of daily living).

All of these definitions illustrate the complexity of the construct of self-awareness but do not, however, fully account for the impact of impaired self-awareness on the individual's everyday life. Thus the following more recent definition is chosen for the purposes of this literature review. Individuals who have impaired self-awareness are defined as having a particular problem when it comes to awareness of their newly acquired disabilities. They have difficulty:

> "understanding that they have deficits, anticipating the impact of those deficits on function and assessing their occupational performance in relation to those deficits" (Dirette et al., 2008a, p.44).

This definition captures the temporal aspect of self-awareness i.e. the ability to look into the future. Furthermore, it acknowledges the complexity of being able to hold knowledge of the present, anticipate the future and then to reflect on the everyday functional performance of an individual's daily occupational experience.

Self-awareness is a more complex multi-dimensional construct that develops slowly across childhood and has a different presentation at different stages of development.

> "Our sense of self is the defining centre of social, emotional and personal development. It is our awareness of self that creates 'personhood' and allows us to organize our subjective experience and our understanding of and relationship to others" (Thornton, 2008, p.148)

It is this more complex construct that is at the centre of this research study.

2.3 Typical development of self- awareness

Development of self follows a protracted course and is not complete and integrated until early adulthood (Harter, 2012a). Additionally, the development of self in childhood is affected by a number of factors. Cognition has a significant impact on development, alongside social, environmental and biological factors that influence the integrated sense of self that develops throughout childhood (Sigelman and Rider, 2003). The increasing cognitive ability of the child enables them to compare and evaluate their abilities in a number of different circumstances. Initially, younger children describe themselves in very concrete and physical terms e.g. 'I'm a boy and I'm really big.' They also tend to overestimate their abilities e.g. 'look how high I can jump – right up to the sky!' With time the older child can compare him/herself to others e.g. how many sums he has completed in a test, or be able to rate his sporting ability against others. However, the adolescent has more of a turbulent time trying to integrate all the different aspects of self into one complete sense of self. For instance, they find it difficult to reconcile how they can be kind and considerate to their friends while being sarcastic and unhelpful in the home.

In addition to cognition, aspects of the child's personality, cultural influences, health, family structure, sibling relationships and social influences also play a part in the way that self develops on an individual basis. Additionally, styles of parenting and teaching are crucial in providing feedback to the young person's developing sense of self but these can be positive or negative and include the impact of abuse and emotional neglect (Hildyard and Wolfe, 2002, Margolin and Gordis, 2000).

Development of self-awareness is a dynamic process that interacts along with other aspects of physical, social, cognitive and emotional development.

2.3.1 **Development theory**

Self-awareness is one of the many constructs of self from a domain that includes self-concept, self-esteem and self-efficacy. Writers on the development of self constructs continue to refer to the early influential writings of William James, a 19th century philosopher (Damon and Hart, 1988, Crispin, 2006, Harter, 2012a). James' work on the theory of self identified the complexity of self and differentiated between the "I" self and the "me" self, providing a philosophy for others to follow (James, 1890). In more recent times, Damon and Hart constructed a model that detailed milestones across childhood within the domains of the "me" self and the "I" self (see Figure 2-1). The "I" self is the "self-as-knower" or self-as-subject represented on the side of this model. The "I" self has an awareness of different aspects of the self, including the continuity and uniqueness of one's life experience. On the other hand the "me" self is the self-as-known or self-as-object represented on the face of this model. It is concerned with the actual qualities of the self across material, social and spiritual domains (Damon and Hart, 1988). Damon & Hart constructed a developmental model of self-awareness based on these principles and a measure based on the model to evaluate the developmental level of children and young people. The Self-Understanding Interview (Damon & Hart, 1988) has been used in a number of studies of typically developing children and those with medical conditions (Malti, 2006, Farley et al., 2010, Plesa-Skwerer et al., 2004).

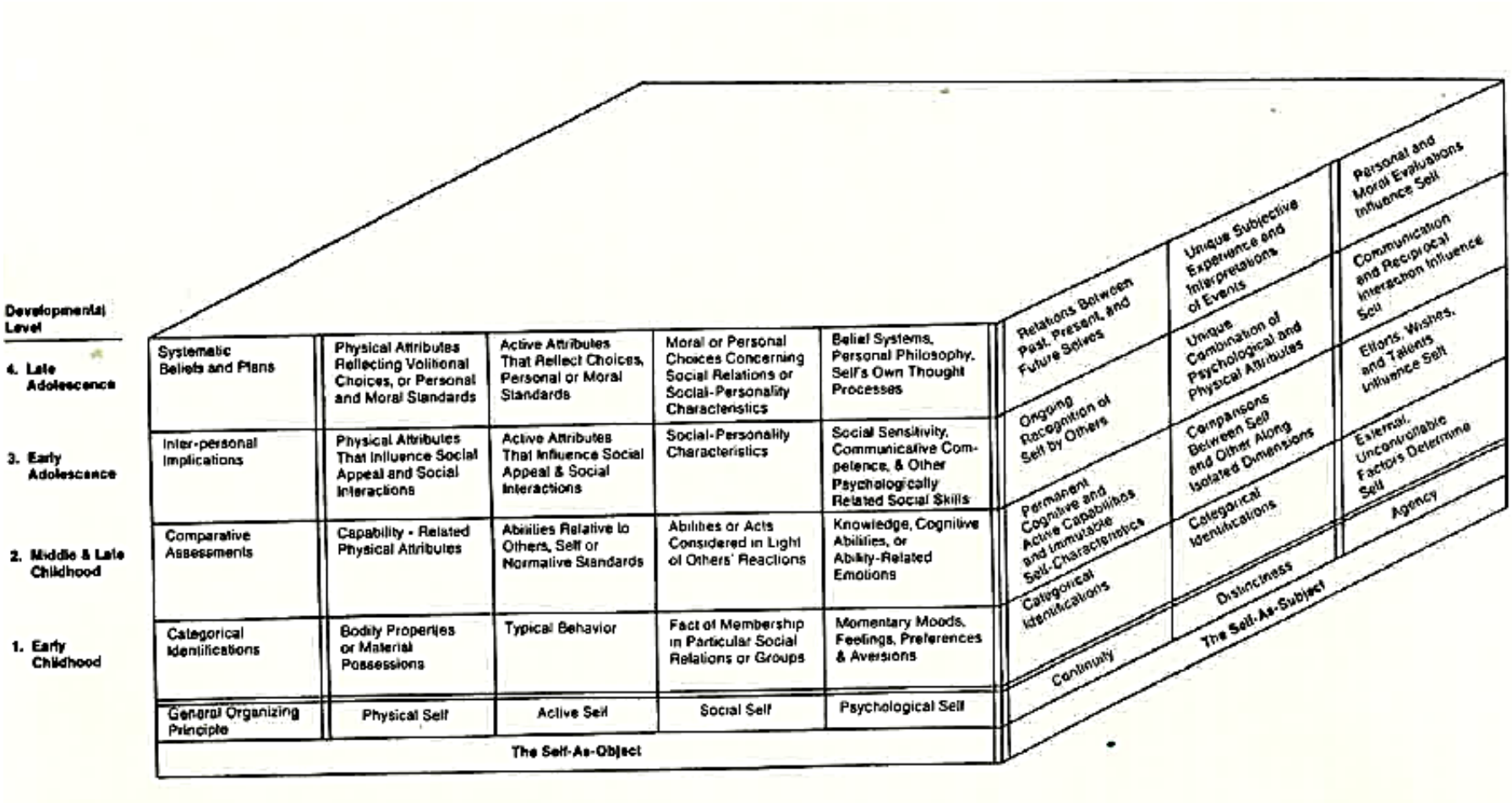

Figure 2-1: Developmental model of self-understanding (Damon & Hart, 1988). Reproduced with permission (appendix 13.14)

Similarly, Harter remained true to the Jamesian tradition and constructed a model (see Figure 2-2) that highlighted the multifaceted nature of self (Harter 2012). Likewise, she also developed a tool for measuring children and young people's level of self-development that has continued to be used in child psychology to assess children and young people of all ages and has also been used to assess children with a range of health conditions (Zafiropoulou et al., 2007, Muris et al., 2003, Lindsay and Dockrell, 2000b).

Both authors highlight the importance of viewing self-development as complex and multidimensional. Neither of the measures that they have developed provides a composite score (Damon and Hart, 1988, Harter, 2012a).

Age period	Salient content	Structure/organization	Valence/accuracy	Nature of comparisons	Sensitivity to others
Early adolescence	Social skills, attributes that influence interactions with others or one's social appeal; differentiation of attributes according to roles	Intercoordination of trait labels into single abstractions; abstractions compartmentalized; all-or-none thinking; opposites; don't detect, integrate, opposing abstractions	Positive attributes at one point in time; negative attributes at another; leads to inaccurate overgeneralizations	Social comparison continues although less overt	Compartmentalized attention to internalization of different standards and opinions of those in different relational contexts
Middle adolescence	Further differentiation of attributes associated with different roles and relational contexts	Initial links between single abstractions, often opposing attributes; cognitive conflict caused by seemingly contradictory characteristics; concern over which reflect one's true self	Simultaneous recognition of positive and negative attributes; instability, leading to confusion and inaccuracies	Comparisons with significant others in different relational contexts; personal fable	Awareness that the differing standards and opinions of others represent conflicting self-guides, leading to confusion over self-evaluation and vacillation with regard to behavior; imaginary audience
Late adolescence	Normalization of different role-related attributes; attributes reflecting personal beliefs, values, and moral standards; interest in future selves	Higher-order abstractions that meaningfully integrate single abstractions and resolve inconsistencies, conflict	More balanced, stable view of both positive and negative attributes; greater accuracy; acceptance of limitations	Social comparison diminishes as comparisons with one's own ideals increase	Selection among alternative self-guides; construction of one's own self-standards that govern personal choices; creation of one's own labels toward which the self aspires

Figure 2-2: Example of normative-developmental changes in self-representations (Harter 2012). Reprinted with permission of The Guildford Press (Appendix 13.14)

Self-awareness develops early in childhood when babies realise that they can have an effect on their world and this concept can be formally tested around the age of 18 months with a mirror dot test (Schaffer, 2004, Sigelman and Rider, 2003). A dot of rouge is placed on the infant's forehead, and from 18 months the infant will look in the mirror and touch the dot on their own forehead, suggesting self-recognition. Self-awareness continues to mature throughout childhood following a developmental trajectory and does not reach full maturity until the third decade of life (Harter, 2012a, Rochat, 2003).

Different ages and stages of childhood are referred to throughout this thesis. The authors describe early childhood, Middle childhood, Late childhood and Adolescence. The age periods for each of these stages will be taken as 4-7 years for early childhood; 8-11 years for middle/late childhood; and 11 years onwards for adolescence. Harter (2012a) also refers to adolescence as early (11-13 years), middle (14-16 years) and late (17 years onwards).

Self-awareness in the developmental context is the ability to stand apart and monitor oneself. This ability to judge oneself relies on a combination of cognitive development and social experiences (Sigelman and Rider, 2003, Thornton, 2008). On the one hand developmental theorists, such as Piaget, describe cognition as a staged process that all children travel through. The uniformity of the staged theory accounts for the transformational change that occurs in this domain (Miller, 2002). On the other hand, environmental and social influences such as parenting, cultural influences, styles of teacher feedback and learning environments give 'variational'

change. In this way our individual differences become apparent (Harris, 2008, Rochat, 2003, Morin, 2006).

Young children have a focus on the material and physical domain (Harter, 2012; Damon and Hart 1988). They are concerned with their material possessions and physical abilities and they tend to overestimate their performance (Harter, 2012). Harter (2012) provides pen portraits, developed from data across many children at different ages. They are very helpful in portraying the key components of each stage. The pen portrait of a child in early to middle childhood contains the comments:

> "I can run even farther than when I was 3. I can throw a football farther, and catch it too! I can climb high, a lot higher than I could when I was little and I can run faster, too. I can also throw a ball real far, I'm going to be on a team some day when I am older" (Harter, 2012, p.50).

Cognitive and metacognitive changes during childhood have a significant impact on the development of self-awareness.

One such change that affects the development of self-awareness occurs in middle childhood. Children learn about learning, and how and when to use strategies to improve their performance. They also develop the ability to reflect and evaluate their abilities in relation to their own personal goals and in relation to others' abilities (Eccles, 1999, Sigelman and Rider, 2003, Harter, 2012a). Erikson identified

this stage as one of *industry versus inferiority* (Stage 4 , 6-12 years). One of the concerns at this time, according to Erikson is "am I competent compared to others?" The concept of comparison is critical to the development of self in middle childhood. The child starts to make comparisons about their competencies and define themselves as being like/not like others (Sigelman and Rider, 2003, Miller, 2002, Eccles, 1999). The child develops a sense of competency and mastery through achievement and a sense of failure when they are less successful (Miller, 2002). This reflective and comparative skill is essential for developing self-awareness.

Another example of cognitive development that relates to self-awareness presents in adolescence, when young people develop their cognitive skills further and higher level cognitive and executive functions become more prominent. Executive function is a complex interaction of a number of cognitive functions such as planning, organising, self-initiation, self-regulation, abstract reasoning and flexible problem solving that are necessary for goal directed behaviour (Anderson and Catroppa, 2005, Ylvisaker, 1998a). The young person has the ability to utilise abstract thinking to shape the nature of self-awareness into an integrated sense of self and can evaluate psychological traits in addition to the previously focussed concrete physical traits (Schaffer, 2004, Eccles, 1999, Harter, 2012a). Critically, the young person also has the ability to master a temporal perspective of self and can integrate a coherent sense of self in the past, the present and the future (Damon and Hart, 1988, Flavell et al., 2002).

Piaget describes a general developmental trend from very specific concrete descriptions of early childhood through more general statements in middle childhood to higher order, abstract descriptions in adolescence (Thornton, 2008). The pre-frontal cortex is responsible for abstract thinking and has a specific period of physiological development in adolescence (Giedd and Rapoport, 2010, Giedd et al., 1999). The newly activated and strengthened neuronal circuits in the frontal lobe facilitate higher cognitive and executive functions such as working memory, inhibition and attentional control. Adolescents become able to manage competing demands on memory and attention and find themselves able to integrate experiences; a skill that is crucial for developing maturity of self.

Like the developmental theorists, the theorists of self-development also describe incremental changes across childhood. However, the difference between development of cognition and development of self is that each stage of cognitive development supersedes the last. The child abandons the less mature functions and uses the new cognitive framework that has been built. The stages of development of self, however, are not mutually exclusive and form more of a common trajectory throughout childhood and into adulthood rather than a clear staged process. There are commonly agreed qualitative differences between children at different ages; however some tendencies remain even when others become more salient. For example, it would still be commonplace to meet an adult who had an overoptimistic sense of his/her ability or someone who described themselves in terms of their material possessions or in the type of concrete terms that the young child does (Thornton, 2008).

2.3.2 Dynamic view of child development

In recent years there has been a shift in thinking to a more integrated view of child development, dynamic systems theory. Scholars have suggested that development is influenced by the dynamic interactions all of the biological, physiological, genetic, environmental and social factors (Case-Smith et al., 2010, Thornton, 2008, Smith and Thelen, 1993). No one factor dominates, but may have more influence at a particular time in the child's development. For example, as the infant develops postural control, there is a dynamic interaction with social development as the infant is now more able to manage eye contact with others. The motor control system is therefore facilitating development in the social system in a dynamic way. In another case a more stimulating environment may encourage a child to move at an earlier stage. There again, there has been a dynamic interaction between the motor system and the environment, causing maturational change in the developing brain

The important message is that the system is integrated and develops in a dynamic manner. Children develop with a similar trajectory but it is not as predetermined and linear as was once thought and there is much more accommodation of individual differences (Thornton, 2008)

2.4 Brain maturation

Recent advances in neurosciences have led to a greater understanding of the prolonged and complicated process of brain maturation through childhood. There is evidence that although maturation of the brain follows an overall trajectory, there is variation in the maturation of different brain regions. Interactive

specialization accounts for the dynamic changes in the brain during development. Inter-regional changes in neuronal connectivity affect changes in the intraregional connectivity in a dynamic manner(Johnson, 2005). Changes in grey matter continue in a non-linear manner across childhood and into adulthood (Gogtay et al., 2004, Giedd et al., 1999, Thomas and Johnson, 2008). After an initial period of neuronal proliferation around birth, the more active neuronal connections become strengthened and neurones become activity dependent and specialised within brain regions. This process is known as interactive specialisation (Thomas and Johnson, 2008).

Another common theme in the neuroscience literature is the presence of sensitive periods / critical periods in brain development. These correspond to a time of rapid development of brain functions when the brain is most sensitive to the effects of experience and environmental influences (Richardson and Thomas, 2008, Thomas and Johnson, 2008). Although the majority of these periods occur pre-natal and around early years, there is a more prolonged period of development in the prefrontal cortex and a second wave of overproduction of synapses during adolescence (Thomas and Johnson, 2008, Gogtay et al., 2004, Giedd et al., 1999).

It is of particular importance that maturation of the frontal lobes is not complete into early adulthood (see Figure 2-3). Grey matter is represented by the red colour on this diagram which gradually changes to white matter with more blue colour on this diagram) across childhood with increased neuronal myelination. As we can see (see Figure 2-3) the brain matures from posterior to anterior both across the whole brain and also within each lobe. Likewise the frontal lobes develop in an anterior

direction with the prefrontal cortex being one of the last areas to develop. The maturation of the frontal lobes is important for two reasons. First, it is important because the frontal lobes are particularly susceptible to damage as a result of TBI (Jacobs et al., 2007, Gogtay et al., 2004). Second, the frontal lobes and especially the prefrontal cortex have an important role in the development of executive and metacognitive skills and have a particular role in the development of self-awareness (Prigatano and Schacter, 1991, Stuss and Anderson, 2004).

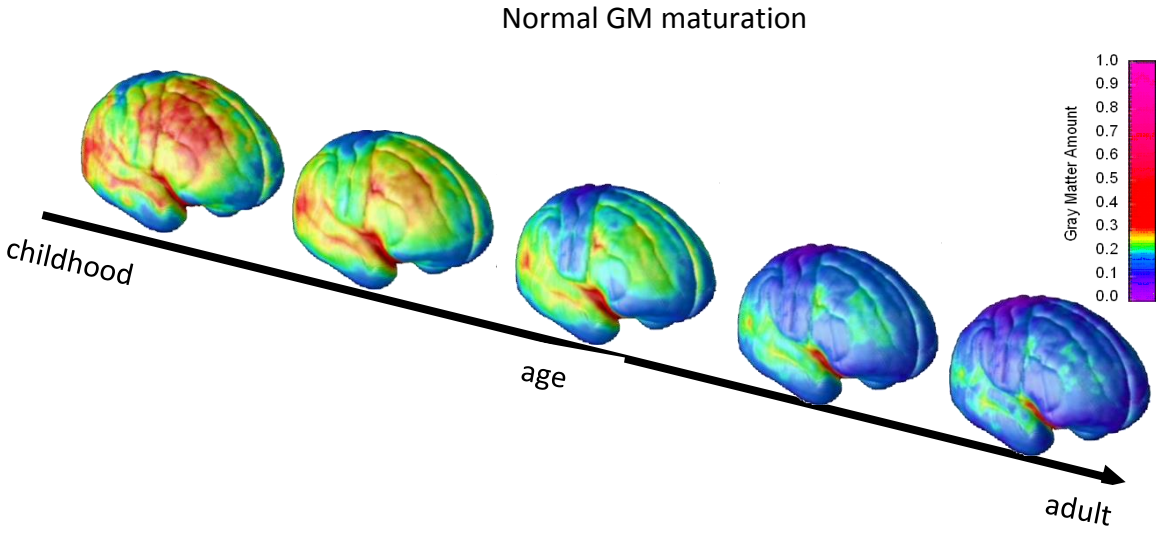

Figure 2-3: Brain maturation (Gogtay, 2004). Reproduced with author's permission (appendix 13.14)

2.5 Brain injury and interrupted development

Brain maturation is a lengthy process that is influenced mostly by natural and occasionally by unexpected events. Traumatic events can occur at any time during development. A brain injury is one such event and the recovery outcomes may be influenced by the length of the period of typical development prior to the injury.

2.6 Brain injury

A brain injury can occur at any time across the life span and can have a devastating and long lasting effect on victims and their families (Anderson and Catroppa, 2006a, Wade et al., 2009). The causes of paediatric brain injury include traumatic brain injury (TBI), stroke, brain tumour, hypoxic damage and infections such as meningitis and encephalitis. A TBI is the most common brain injury in childhood and is an injury caused by an external force including road traffic collisions, assaults, gun shot and penetrating injuries.

The number of children who sustain a head injury each year is significant and head injury remains the major cause of death and disability amongst children and young people in the UK (Sharples et al., 1990, Thornhill et al., 2000). In the United Kingdom, the total rate of hospitalization following a head injury ranges from 280-500 per 100,000 for those under 16 years (NHS NHS England, 2013). It is difficult, however, to ascertain accurate data for children following TBI in the UK as the definition of child varies and TBI, head injury and brain injury are all used in data collection studies. The process of extracting child TBI subset data from all age population studies is therefore a complex matter. One large-scale population-based study of children who required a hospital admission following a TBI showed an incidence of 280 admissions per 100,000 population in one particular health district over a six year period (Hawley et al., 2003). This is a key study as it uses the specific diagnostic term of TBI, defined in this study using the Glasgow Coma Scale (GCS) classification and gathers data on a paediatric population. This incidence figure is higher than the all-age figure mentioned above but is in line with the

regional variation factor of 4.6 (Tennant, 2005). It also reinforces the earlier observation of a peak incidence of head injury in children under 15 years of age (Tennant, 2005). The events that lead to a TBI vary across childhood. Whereas falls and non-accidental injuries are more common in babies/infants, there is a higher incidence of pedestrian and road related accidents in older childhood (Hawley et al., 2004, Parslow et al., 2005).

Whilst a brain injury is not a life limiting condition and despite data gathering difficulties, it can still be concluded that the prevalence of children living with the effects of TBI in childhood is a significant number that presents a major public health issue (Yates et al., 2006). National Specialist Commissioning has been introduced in the UK for specialist rehabilitation services (NHS Commissioning Board, 2012) and one of the expectations is that all brain injury rehabilitation services will provide data to a central database (UK Rehabilitation Outcomes Collaborative). Centralizing some of the systems will help us to have more accurate data in the future.

2.7 Recovery and rehabilitation following a brain injury

Children who sustain a brain injury in childhood present with a range of motor, sensory, cognitive, communication, social and behavioural deficits that persist throughout childhood and have an ongoing impact on the child and their family (Anderson and Catroppa, 2006a).

At the centre of our knowledge of recovery from a brain injury in childhood is a debate between an early vulnerability model and an early plasticity model. On the

one hand, there is a long held position that a young brain is adaptable and can benefit from its ability to shape and change, known as plasticity (Tucker, 2006, Anderson et al., 2011, Johnston, 2009). The adaptability of the young brain is a crucial part of what came to be known as the Kennard Principle[1]. On the other hand, a more contemporary view holds that the younger the child, the less foundation has been laid down and the child moves forward through childhood with an injured brain. It is more difficult for the child/young person to acquire new skills without the previously acquired skills being intact. The child is said to grow into their disability or have emerging difficulties as the demands of their activities increase (Levin et al., 2004, Anderson et al., 2009a, Dennis and Levin, 2004) . In the cognitive domain, there is a dose-response relationship between the severity of the brain injury and the recovery of cognitive performance i.e. a more severe brain injury will produce a greater cognitive deficit. Thus children who have sustained a severe brain injury at a younger age fit what is called a "double hazard" model (young AND severe) and do not make developmentally appropriate gains in their abilities to function independently at home, school and play (Babikian and Asarnow, 2009, Anderson et al., 2009b, Forsyth and Waugh, 2010).

The paediatric brain injury literature indicates that injury severity and age at injury are not the only factors that affect the outcome of brain injury in childhood. Other factors such as premorbid health conditions, family resilience and socio-economic status (SES) contribute to long term outcomes, with an increasing body of evidence suggesting a link between childhood brain injury and homelessness, crime and

[1] The Kennard Principle is named after Margaret Kennard, a leader of brain lesion research with a far reaching scope (see biographical report by Maureen Dennis, 2010)

mental health disorders in adult life (Williams et al., 2010, Max et al., 1998). This wide range of influential factors leads to children with brain injury being a heterogeneous group with significant variability in a range of injury and environmental characteristics.

While the vulnerability versus plasticity debate continues, a new position has recently been suggested of a recovery continuum with plasticity and vulnerability at the extreme ends (Anderson et al 2011). The additional factors of age, environment and rehabilitation influence the amount of recovery achieved along the suggested continuum (see Figure 2-4)

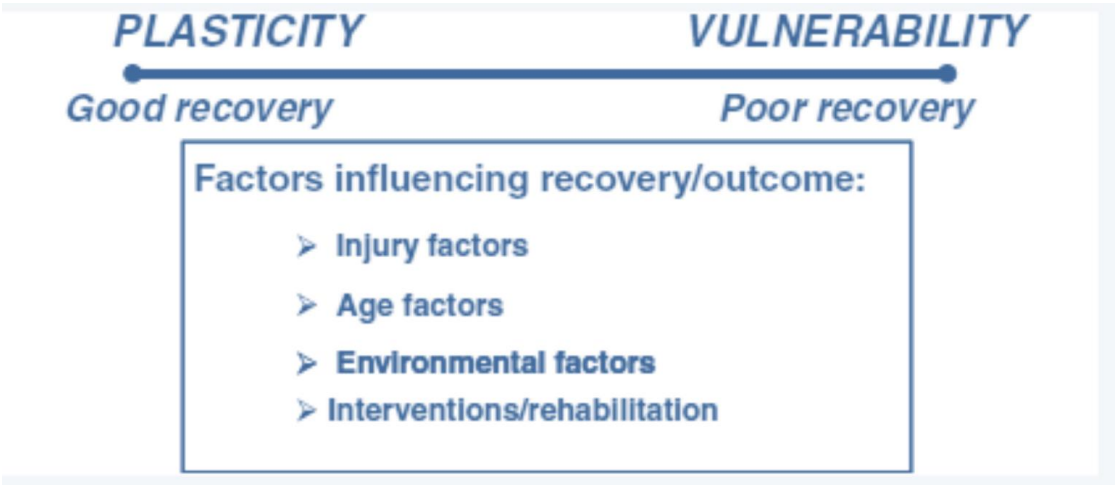

Figure 2-4: Recovery from early brain insult - a continuum? (Anderson et al, 2011) Reproduced with permission of Oxford University Press (appendix 13.14)

The long-term consequences of brain injury are beginning to be acknowledged. Data are being published from longitudinal studies (Anderson et al., 2012, McKinlay et al., 2009) and a brain injury in childhood is beginning to be recognised as a

lifelong condition[2]. Long term cognitive and psychosocial difficulties are among those highlighted as being particularly chronic; continuing to impact on long term participation in home, school and community (Donders and Warschausky, 2007, Galvin et al., 2010, Hawley, 2005). Children and young people themselves continue to report tiredness, sensitivity to loud music and fear of seizure affecting their participation in leisure activities long-term (Renstrom et al., 2012). Whereas families continue to report ongoing concerns with behaviour and social more than physical and cognitive problems (Yeates, 2012, Wade et al., 1996).

Rehabilitation is one of the factors that is purported to influence the recovery trajectory of children and young people and has an impact on their long term outcomes (see Figure 2-4). The British Society of Rehabilitation Medicine (BSRM) defines rehabilitation as:

> "a goal-directed process which reduces the impact of long-term conditions on daily life" (British Society of Rehabilitation Medicine, 2008, p.2).

The Children's Trust is the UKs leading charity for children with an acquired brain injury. The team at The Children's Trust acknowledged that the definition above had been developed in relation to adult rehabilitation services and introduced a children and young people's perspective by defining rehabilitation as follows:

[2] Recent conferences (October 2013, Newcastle and March 2014, San Fransisco) held by International Paediatric Brain Injury Society have had the title "Should Paediatric Brain Injury be Treated as a Chronic Condition? An International Perspective" http://www.ipbis.org/index.html

> "Rehabilitation seeks to enable children, young people and their families return to their lives as successfully as possible following a brain injury" (The Children's Trust, 2012).

While the National Institute of Health and Clinical Excellence (NICE) provides guidance for the early intervention following a head injury[3], there is no definitive guidance in the UK for the rehabilitation of children and young people following a Traumatic Brain Injury. Recent contractual guidance for rehabilitation services for children and young people contains aims and objectives for service provision (NHS England, 2013) but it is directed at a wider population including those having an acquired brain injury and an acquired spinal injury. A second document may also be informative for this client group (Royal College of Physicians, 2003). In order to ensure "consistency and knowledge of best practice" for rehabilitation services following a stroke in childhood, the Royal College of Physicians, London, produced a set of guidelines that may be useful to inform some practices in rehabilitation following a TBI. Specifically, the report gives guidance about the theoretical underpinnings of rehabilitation services and two of the guidelines need further attention:

1. Each team should use a consistent framework and terminology in providing care to the child affected by stroke
2. It is recommended that the World Health Organisation's International Classification of Functioning (ICF) terminology is used

[3] NICE guidelines [CG176] published January 2014 is available https://www.nice.org.uk/Guidance/CG176

The World Health Organisation's International Classification of Functioning (ICF) is promoted in these guidelines. The ICF is a conceptual framework that has replaced the medical model in recent years, recognising the importance of social and cultural aspects of disability, in addition to the health condition itself (Simeonsson, 2009). The ICF has a focus on function rather than on disability/impairment. In 2007 a children's version of the ICF was published to "record the characteristics of the developing child and the influence of its surrounding environment" (World Health World Health Organisation, 2007, Ballert et al.). The ICF-Children and Youth version (ICF-CY) has the same structure and classification system as the original ICF. The ICF-CY is organised in two parts. The first part is concerned with **Functioning and Disability** and has two components – **Body** component (body functions and structures) and an **Activities and Participation** component. The second part concerns **Contextual Factors** that include **environmental** and **personal** factors.

The ICF classification is not concerned with the process of disability but provides a means of classifying and describing the complex interactions between the health condition and all of the related factors as they relate to individuals. It provides a common language and definitions that can be used to describe the complex interactions involved in disability. All of the components interact in a dynamic manner and the relationships are represented in Figure 2-5.

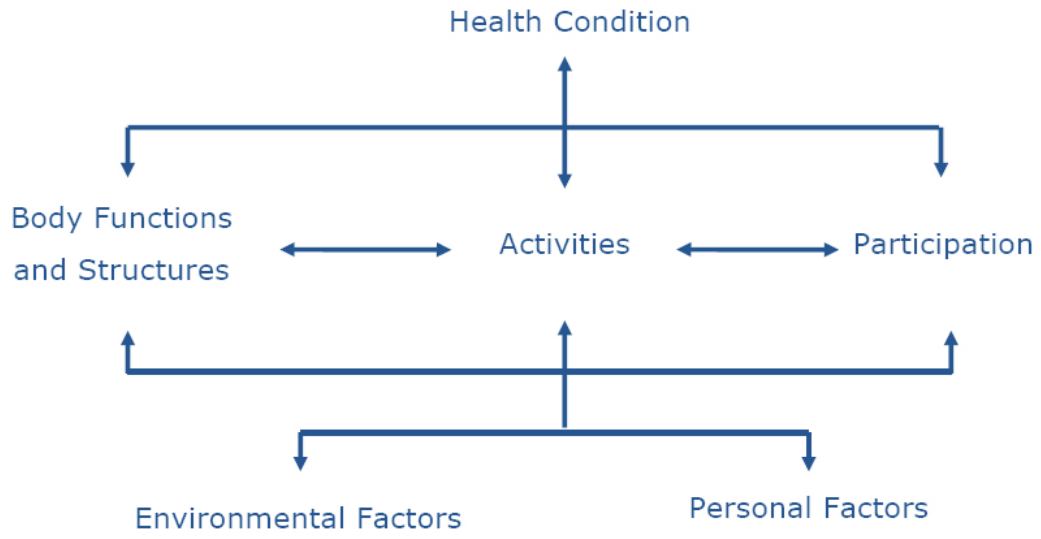

Figure 2-5: Interactions between the components of the ICF (WHO, 2007). Reproduced by permission of World Health Organisation (appendix 13.14)

The model in Figure 2-5 can be used to apply any health condition providing a useful common language at an individual, group and institutional level. At an institutional level the model can aid strategic service development and delivery that reflects the broad needs of those with the particular health condition (Laxe et al., 2013, Tempest et al., 2012). Furthermore, at an individual level they can be used to describe a situation in detail and aid goal setting (Dalen et al., 2013). An exemplar of using the ICF-CY at an institutional and an individual level is described in a recent article (Martinuzzi et al., 2010). The authors illustrate how the clinical team was educated and given examples of how the child and family goals were set in relation to the ICF-CY to include personal and environmental factors as well as activity goals. The increased profile of the ICF and ICF-CY in the rehabilitation literature will help

clinicians and researchers to articulate the complexity of brain injury and recovery in childhood within a dynamic developmental context.

One of the factors that affects the child and young person's ability to benefit from the rehabilitation process is a difficulty recognising their newly acquired disability and engaging in the rehabilitation programme (Marcantuono and Prigatano, 2009). The children/young people experience a number of losses such as loss of abilities, loss of future aspirations and loss of friendships. Understandably the child and family find it difficult to engage with clinicians and set rehabilitation goals (Marcantuono and Prigatano, 2009, Ylvisaker, 1998b) A recent review of child and family goals in a rehabilitation setting found that the goals were mostly assigned to the activity/participation component of the ICF-CY, particularly the mobility and self-care domains (Kelly et al., 2013). The children, young people and families were more able to articulate these immediate and obvious activity goals.

2.8 Brain injury and self-awareness

As mentioned previously, there are a number of significant long term sequelae following a TBI particularly in the cognitive and psychosocial domain (Anderson and Catroppa, 2006b) that will have an impact on self-awareness. The frontal lobes have a particular role to play in cognitive and psychosocial function and are implicated here for two reasons. First, they are unfortunately susceptible to damage due to the mechanical forces of a traumatic brain injury. The brain moves forward and backwards within the skull during an acceleration/deceleration injury and tearing and shearing forces act on the tissue of the frontal lobes. Additionally, we have seen above that the frontal lobes are the last brain area to have neuronal

maturation and will not be completely matured when the child/young person sustains their injury (Gogtay et al., 2004). Neuropsychological consequences resulting from such an injury are evident in the early recovery stage and remain persistent in the long term. Not only has goal setting in the early stages of recovery been identified as unrealistic (Ylvisaker, 1998a) as a result of deficits in self-awareness (Stuss and Anderson, 2004), but a recent 10-year follow up study highlighted the ongoing difficulty of executive functions, especially speed of processing and goal setting (Beauchamp et al., 2011).

The issue of impaired self-awareness receives much attention in the adult brain injury literature. Impaired self-awareness is cited as one of the major negative influences on long term adult outcomes (Hart et al., 2009). Impaired self-awareness is a key issue because it leads to poor engagement in rehabilitation and individuals remain resistant to using strategies and supports in their everyday lives (Livengood et al., 2010, Dirette, 2010). For example the young person may not appreciate the need to integrate strategies, such as taking extra rests or using prompts and checklists of what to take to school, into their everyday life. Additionally, they may not understand the impact of subtle social communication deficits on their friendship group. These events may be the beginning of a chain of events that cause the young person to disengage and make alternative lifestyle choices. There is emerging evidence of a significant number of individuals in the prison population who have sustained an earlier TBI in childhood (Williams et al., 2010).

While impaired self-awareness is an important clinical issue in the paediatric neurorehabilitation setting, there is currently no multi-professional consensus regarding this complex and multifaceted phenomenon. In part, the lack of clarity regarding theoretical constructs is a consequence of the fact that the concept of self-awareness is of interest in many fields of science and different clinical disciplines (Toglia and Kirk, 2000). Understandably the definitions and views of self-awareness vary depending on the theoretical and professional lens. Unfortunately, each discipline has a different conceptualisation, comes from a different perspective and has its own terminology related to self-awareness e.g. executive functions, identity, metacognition, perceived competence, self-efficacy or autonoetic consciousness i.e. the ability to become aware of oneself in the past, present and future (Hanten et al., 2004, Wheeler et al., 1997, Missiuna and Pollock, 2000). It is important that the theoretical perspective in this study is relevant to occupational therapy clinical practice whilst being informed by related theoretical frameworks.

Recent adult literature contains encouraging results regarding an individual's ability to recognise their difficulties more easily when they are carrying out tasks that they had mastered pre-injury (Dirette et al., 2008a). The importance of assessing and treating self-awareness within the context of occupation is highlighted.

2.9 Occupational therapy and self-awareness following a brain injury in childhood

Occupational therapy is notoriously difficult to define and not unanimously agreed upon. In the United Kingdom, the College of Occupational Therapists (College of

Occupational College of Occupational Therapists, 2010) define occupational therapy as follows:

> "Occupational therapy enables people to achieve health, well being and life satisfaction through participation in occupation." (College of Occupational Therapists, 2010)

Occupations are those tasks that a person needs to, wants to or is expected to do in their everyday life, and meet the human need for self-care, enjoyment and participation in society (College of Occupational College of Occupational Therapists, 2010). In childhood, these occupations include playing, getting dressed, eating and managing personal care needs, household chores, schoolwork and extracurricular activities such as clubs and learning instruments (Rodger, 2010a). While on the one hand occupational therapy is sometimes seen as "common sense", Turpin and Iwama suggest that it is, in fact, more like "uncommon sense" (Turpin and Iwama, 2011, p.1). Ultimately, occupational therapy is described as a complex intervention (Creek, 2003, Creek et al., 2005).

The complexity of the occupational therapy intervention is a result of the many elements that interact in a dynamic and unpredictable manner. These elements include the therapist, the child and family, the context, the environment and the therapist's actions. The already dynamic elements are in turn influenced by other factors but there is no simple way of picking out which are the active ingredients that may be interacting at any given time (Creek et al., 2005).

Taking the case of brain injury in childhood and using the ICF-CY framework we can see that for the child alone a range of injury factors (e.g. memory, motor

impairments, self-awareness), personal (e.g. individual and family resilience) and environmental factors (e.g. physical environment and attitudes to disability) can influence their ability to participate in everyday occupations.

A range of conceptual models have been published in occupational therapy textbooks and literature since the 1960's. These theoretical models help to explore and explain something of the meaning and key underpinnings of occupational therapy; and each has occupation at its core.

While other models have been evaluated, the Person-Environment-Occupation model has been chosen as a theoretical framework for this study. An important principle of the current study is that it will be embedded in child development. The Kawa model (Iwama, 2006) and the Model of Human Occupation (Kielhofner, 2008) have also been evaluated as they both take a lifespan perspective. The Kawa model is unique in that it uses the metaphor of a river and reflects the Japanese culture by using elements of the river – river bed, rocks, water and driftwood to represent the context of a person's life circumstances. The context is very important and the environment in which a person lives and the social roles that the person may have affect how the river flows (river bed and walls). The life flow may be interrupted by life events (rocks) and the personal character and skill of the individual (driftwood) are carried along in the river and affect the flow of the river. This type of imagery fits well in some local contexts and has been applied to occupational therapy practice in order to counteract the criticism that other occupational therapy models contained too much Western culture and value (Iwama, 2006, Turpin and Iwama, 2011).

The Model of Human Occupation (MOHO) also has a life span perspective. It emphasises that human occupation changes across time as age and circumstances change (Turpin and Iwama, 2011). MOHO is concerned with an individual's participation in and adaptation to life events. It pays particular attention to the personal characteristics of motivation, life roles and routines, and the influence of the environment. The theory supports the idea that personal capacities and motives are enhanced through engaging in occupation (Kielhofner, 2008). Such engagement is prone to change through the normal life course and particularly in the event of a traumatic life event.

Although both of these models have their merits, they lack the immediate applicability to a children's multidisciplinary environment. Children/young people recovering from a brain injury are often in a multidisciplinary setting and it is hoped that the results of this study will be accessible to a range of clinicians. The Kawa model uses metaphoric language and the MOHO model uses less familiar terminology of volition, habituation and performance capacity (Kielhofner, 2008, Turpin and Iwama, 2011). So, on balance the Person-Environment-Occupation (PEO) model was favoured for this study. The section above on the dynamic systems theory receives positive acclaim. It is topical in children's services to consider the dynamic nature of child development, and the PEO model uses a similar conceptual framework of dynamic interactions having an impact on a child's performance.

The main elements of the PEO model are three dynamic interlocking circles that represent the person, the environment and the occupation (see Figure 2-6). The

dynamic nature of this model is well suited for this study. As we have seen above recent approaches to child development emphasise the dynamic interaction between the personal and environmental factors associated with the growing and maturing child.

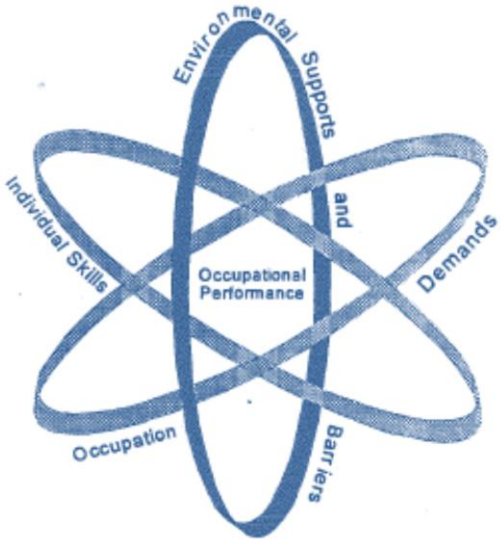

Figure 2-6: PEO model (Law et al 1996). Reproduced by permission of Canadian Journal of Occupational Therapy (Appendix 13.14)

In the centre of the PEO model is occupational performance defined as "the outcome of the transaction between the person, environment and occupation" (Law et al., 1996 page 16). The circles overlap and interact continually and in a dynamic manner. Visualising the overlap of the different dimensions lets us see that the greater their compatibility the greater the occupational performance – "optimal occupational performance". The model is concerned with the "fit" of the circles (Law et al., 1996, Turpin and Iwama, 2011). The degree of overlap in the model may change from time to time in response to ongoing development, life events and contexts (see Figure2- 7). The degree of occupational performance is

described as being more or less congruent and is represented figuratively as a smaller or larger coloured area in Figure 2-7.

It is very helpful to use this visual model to conceptualise the occupational performance of a young person following a brain injury. The person and the environment have both changed abruptly and traumatically. The child/young person discovers that they are no longer able to perform many of the meaningful occupations that they had previously; and the degree of congruence between all these factors is greatly reduced.

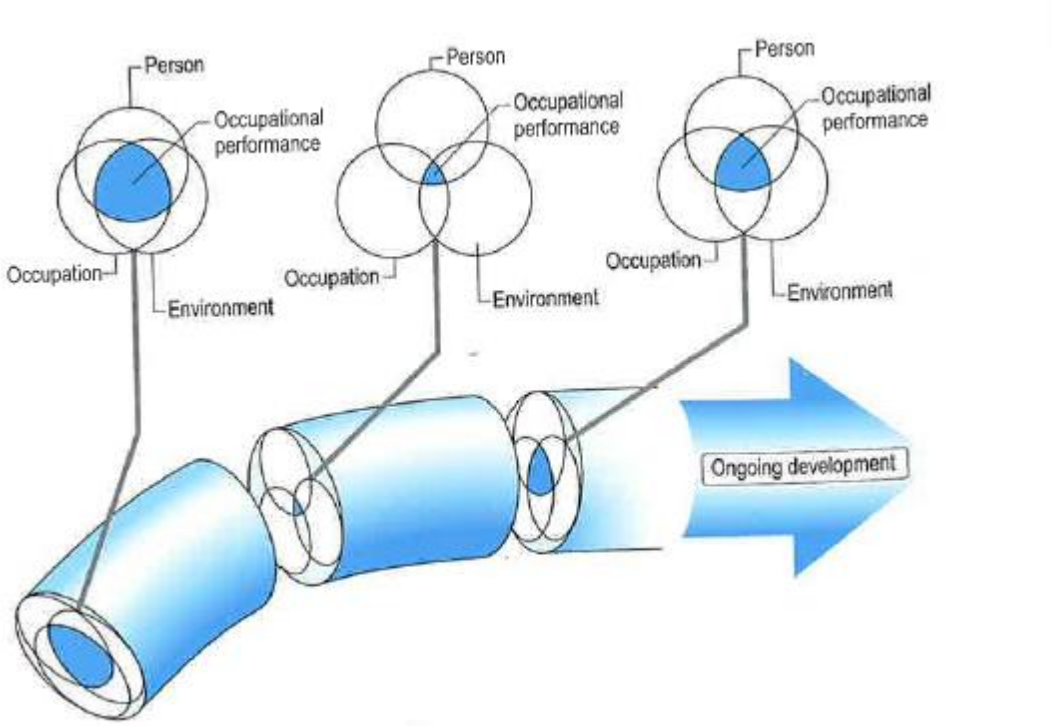

Figure 2-7: Lifespan dimension of PEO model (Law, 1996). Reproduced with permission of Canadian Journal of Occupational Therapy (Appendix 13.14)

The aim of rehabilitation and occupational therapy in particular is to maximise the fit of the three components of the model. The dynamic nature of the model indicates that changing one aspect of occupational performance may have an

overall effect. Changing the environment, for example, to enable a young person to return to school will have an effect on his/her motivation (i.e. the person dimension). He/she will be more inclined to resume some of the previous school work (i.e. occupation) and there will consequently be greater overall effect on his/her occupational performance (Law et al., 1996).

Having occupation at the centre of our professional thinking was endorsed in a recent qualitative study that examined values and philosophical underpinnings of occupational therapy theory (Drolet, 2014). The author determined that occupational performance is a central value to our profession. Current trends in children's occupational therapy have echoed this with a recent growth in occupation-centred practice publications and events[4] (Canadian Association of Occupational Therapists, 2009, Rodger, 2010b, Lane and Bundy, 2012). Children's occupations are those activities that are "meaningful to them, provide fulfilment, and engage them in everyday life with others" (Law, 2002 page 640). They include tasks within the domains of self-care, productivity and leisure. The tasks within the self-care domain vary across childhood and youth from washing, dressing and toileting, to grooming and managing their own health. Productivity includes schoolwork, jobs within and outside the home, and leisure varies from organised to free leisure and play time, such as Girl Guides, swimming lessons and playing Lego at home. Again this will occur inside and outside the home and will be more or less directed by adults with increasing age. Using the PEO model, the level of

[4] Count Me In! was the title of a recent conference (May 2014, London) following the launch of the Children and young people's occupations, health and well being: a research manifesto for developing the evidence base http://www.thechildrenstrust.org.uk/page.asp?section=2010&sectionTitle=Count+me+in

occupational performance will vary as described depending on the demand of the task, the skill of the individual and the environment that the task is performed in.

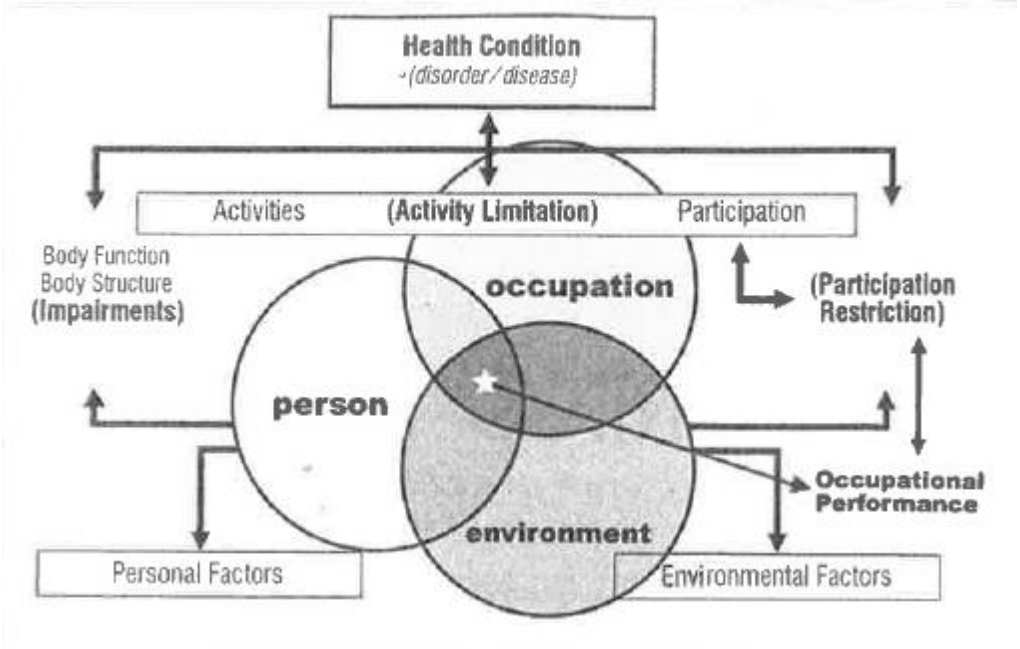

Figure 2-8: International Classification of Disability and Function interacting with PEO model (Law et al., 2005b). Reproduced with permission of World Health Organisation (Appendix 13.14)

A final endorsement of the PEO model for this study is its compatibility with the ICF-CY (see Figure 2-8). The PEO and the ICF-CY both take a holistic and dynamic view of the individual with a disability (health condition, body functions/structures) within the context of their environment and their ability to carry out their everyday occupations (activity, participation and personal factors). Children and young people who have had a brain injury find themselves in a new situation. They have a new health condition which has a far-reaching effect across the ICF-CY model. Their participation is reduced as a result of changes to their body functions and structures, which in turn have an impact on the activity and participation domain.

Environmental factors, including their own prejudices, affect them in a new way and the child/young person has to navigate all of this with an injured brain.

Self-awareness is one of the body functions identified in ICF-CY[5]. Self-awareness is an important element of childhood occupations because in order to achieve a meaningful occupation, there has to be a balance between the challenge of the activity and the skills of the individual (Law, 2010). In the children's setting, it is the adults around the young child who initially create situations to make occupations meaningful. Over time the child has a history of "doing" that informs what they might choose to do in the future and children become aware of the capacities that they might have (Hocking, 2009). As we have seen above, the frontal lobes play an important part in enabling children and young people to develop the ability to evaluate their capacities. Furthermore we have seen that the frontal lobes are vulnerable to damage in a brain injury. It is reasonable to infer that children and young people with an impaired ability to evaluate their capacities following a TBI may require additional support to set realistic occupational goals and to evaluate the outcome of their performance. A deficit in goal setting and evaluation, depending on age, may restrict the child's willingness to adopt strategies in their everyday life and may lead to restrictions in their participation in the school and community setting. Children and young people may make inappropriate choices of activities that do not match their competencies and may lead to poor self-esteem or more risk taking activity than typically expected during adolescence.

[5] ICF-CY classification codes relevant to self-awareness in the body functions/structures category
B11420 Orientation to self
B1644 Insight
B1800 Experience of self

Within the field of rehabilitation following brain injury in childhood, the aspect of self-awareness that concerns the occupational therapist most is the notion of awareness of deficits. The construct of awareness of deficits is most relevant to this particular area of clinical practice because the occupational therapist works alongside the child and family in the recovery phase of brain injury in order to improve the child's performance in everyday activities. Failure on the part of the child/young person to accurately assess their capacities i.e. their ability to manage a task in light of their newly acquired deficits, may result in a failure to engage with the therapists and a failure to use strategies to support their deficits. Additionally, there may be an increased risk that the child/young person may attempt tasks that are beyond their capabilities (Ownsworth and Fleming, 2005).

2.10 Summary

This chapter has introduced the concept of self-awareness, both as a developmental construct, and as it relates to brain injury. The clinical settings of rehabilitation, and specifically occupational therapy, have been introduced. Finally, the importance of self-awareness to occupational performance has been explained.

Having established self-awareness following a brain injury in childhood as an important issue, the following chapter will explore the current evidence through a systematic search of the literature.

3 Chapter 3: Literature review

3.1 Chapter overview

This chapter outlines the formal literature review for this study. An account of the literature review carried out for this study was published in the British Journal of Occupational Therapy (Wales et al 2013) and is included in Appendix 1. Some of the content will be replicated in this chapter.

3.2 Method

3.2.1 Search strategy

The initial literature research strategy involved accessing on-line medical library search facilities sourcing Ovid Medline, CINAHL, EMBASE, AMED PsycInfo and the Cochrane Database.

The following terms were chosen for a literature search (see Table 3-1). Limits of language (English), human and age (all child) were applied to the searches. No limits were set on years of publication:

Table 3-1: Literature search terms

Concept 1	Concept 2	Concept 3
self awareness	child*	brain injur*
self-awareness	pe?diatric	traumatic brain injur*
insight		TBI
impaired self awareness		
ISA		

Inclusion criteria

- articles with full text available in English
- a focus of brain injury in childhood

- address the concept of impaired self-awareness as the main issue

Exclusion criteria

- adult studies
- studies where the abstract refers to the reader gaining insight into or gaining awareness of an unrelated issue e.g. diabetes management

3.2.2 Data analysis

As the data were likely to be primarily qualitative, the key themes were established from reading and evaluating the literature. The McMasters' critical review forms were used to critically appraise the literature (Letts et al 2007). McMaster's forms have a quantitative and qualitative evaluation version of forms and guidance notes. The forms and guidance notes are a step-by-step guide to help the reader to evaluate the quality of research papers. The questions cover all aspects of research process including sampling, design, analysis etc.

This evaluation exercise increased the familiarity with the content and quality of the articles. The articles were sorted according to their methodology or their area of clinical practice. The qualitative papers were evaluated and assigned a level of evidence using a system described by (Cesario et al., 2002). A scoring system was used to ascertain quality of each study. The studies were scored in five sections:

1. Descriptive vividness
2. Methodological congruence
3. Analytical Preciseness
4. Theoretical connectedness
5. Heuristic relevance

Cesario and colleagues provided explanatory notes for each of the five sections, two of which had subsections, and a score of 1-3 was assigned to each of the total of ten subsections:

> 3 = Good = 75%–100% criteria met
> 2 = Fair = 50%–74% criteria met
> 1 = Poor = 25%–49% criteria met
> 0 = No evidence that criteria met = < 25% criteria met

The scores were converted to one of three levels of evidence (QI-QIII) where QI indicates a high-level well-constructed qualitative study.

> QI: Total score of 22.5–30 indicates that 75% to 100% of the total criteria were met.
> QII: Total score of 15–22.4 indicates that 50% to 74% of the total criteria were met.
> QIII: Total score of less than 15 indicates that less than 50% of the total criteria were met.

The quantitative literature was evaluated using the McMaster guidelines and assigned a level of evidence using the Oxford Centre for Evidence-based Medicine – Levels of Evidence (Phillips et al 1998). Evidence was graded using a 5 level system where level I is the highest level of evidence and indicates a Randomised Controlled Trial (RCT) with follow up of more than 80%, or a systematic review of RCTs. Level 5 is the lowest level of evidence and indicates evidence that reports expert opinion (see Table 3-2).

Table 3-2 Levels of evidence for quantitative literature

Level	Level of evidence
1a	Systematic review (with homogeneity) of RCTs
1b	Individual RCT (with narrow confidence intervals)
1c	All or none
2a	Systematic review (with homogeneity) of cohort studies
2b	Individual cohort studies (including low quality RCT; e.g. <80% follow-up)
2c	"Outcomes" research; ecological studies
3a	Systematic review (with homogeneity) of case-control studies
3b	Individual case-control studies
4	Case series (and poor quality cohort and case-control studies)
5	Expert opinion without explicit critical appraisal, or based on physiology, bench research or "first principles"

The mixed methods literature was evaluated using the Mixed Methods Appraisal Tool – MMAT (Pluye and Hong, 2014). The MMAT has criteria against which to rate the qualitative, quantitative and mixed method components of a Mixed Methods study. The study is graded as meeting 25% (*), 50% (**), 75% (***) or 100% (*) of the criteria.

A data display in the form of a mind map was used to link and synthesise ideas (Miles and Huberman, 1994). The literature was reviewed and presented visually to

establish the concepts that were similar, and examine those that were different. Although greater confidence is to be placed in emerging ideas that are similar and replicable, in this emerging area of research, the differing findings are equally significant as new understandings are still being constructed (Huberman and Miles, 2002).

3.2.3 Results

The search yielded 276 articles. An additional article was sourced from an information booklet at a brain injury conference. The titles and abstracts of these articles were screened using the inclusion/exclusion criteria. 250 articles were excluded as a result of the exclusion criteria.

The adult literature yielded two further articles as there were teenagers/ adolescents in the sample population (see figure 3-1).

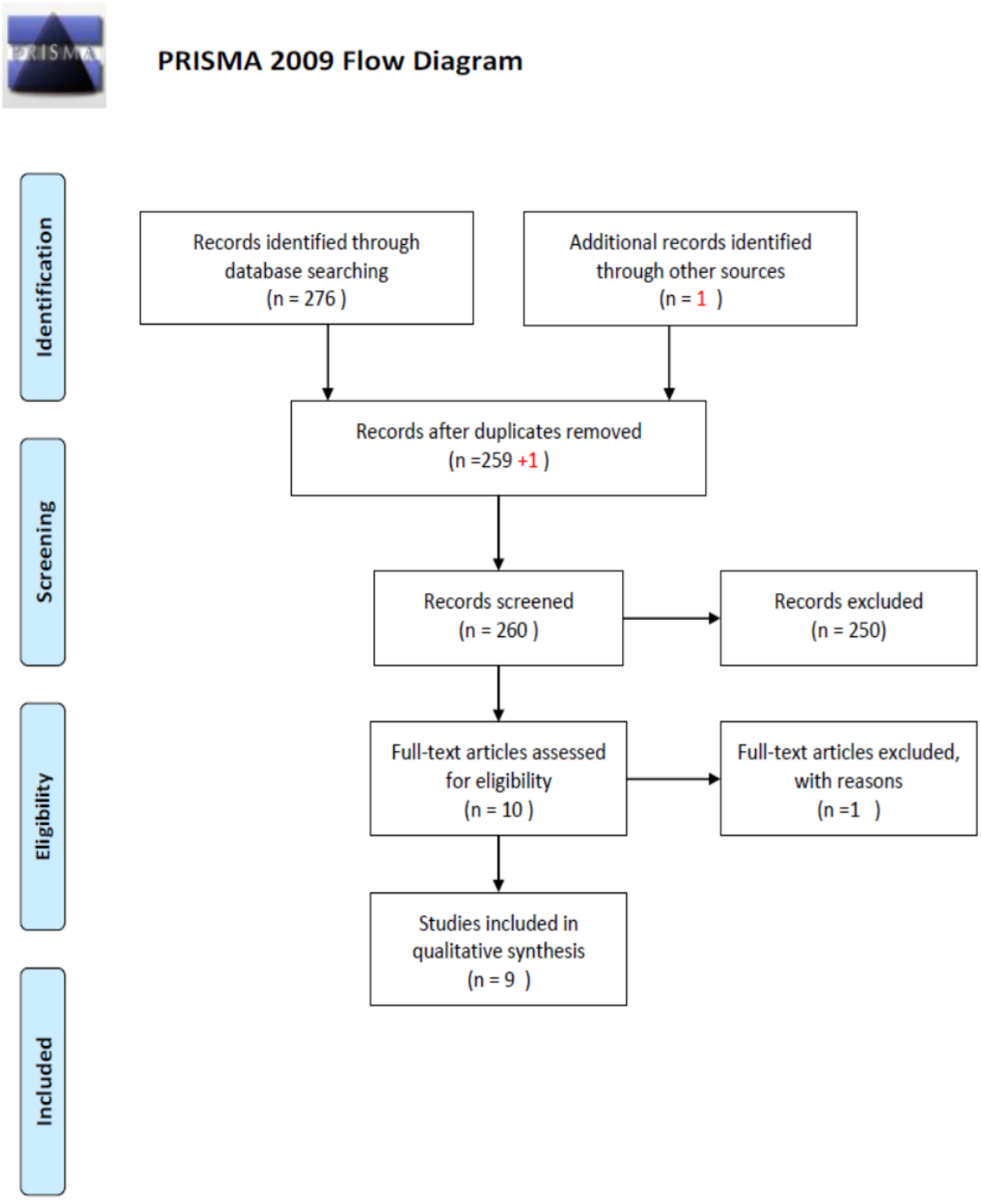

Figure 3-1: Prisma diagram of process of acquiring articles for review[6]

6

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

Full texts were acquired in these ten cases and all were read and evaluated. One paper was rejected as the specificity of topic area had limited clinical utility to OTs working in the field of brain injury in childhood (Newsome et al., 2010).

The remaining studies (n=9) were classified initially by methodology. There were three papers that addressed theory and guidelines for practice (Stuss and Anderson, 2004; Marcantuono and Prigatano, 2008; Gracey et al., 2010)two case studies – one descriptive, one mixed methods (Jacobs, 1993; Zlotnic, 2009), three case-control studies (Josman et al., 2000a) and one experimental study (Beardmore et al., 1999).

All nine papers were assessed for quality. The three papers that focussed on theory and guidelines for practice were not assigned a level of evidence. Assigning levels of evidence to this literature was not appropriate (Cesario et al., 2002). However, it was appropriate to appraise them within the context of the Medical Research Council guidelines for developing and evaluating complex interventions (Medical Research Council 2008). This robust framework has been revised to incorporate a more dynamic approach to evaluating theory building. Theory building is no longer viewed as a first and pre-clinical stage of emerging evidence. Emerging theory should be reviewed and revised to link to emerging research. In the current literature review, three theory papers have been sourced. They have been written by experienced researchers who are well respected in the field of brain injury. They are writing within the context of other relevant theory and demonstrate sound knowledge of the clinical and academic issues. They incorporate case studies and neuroscience/ neuropsychological concepts into their writing. They draw from

adult and developmental perspectives and all three of these papers should be considered as high quality.

One of the studies was qualitative in nature and was evaluated and assigned a QI level of evidence using the levels described by Cesario et al (2002). See Table 3-3 for the scoring system results for this paper.

Table 3-3 Scoring of qualitative literature using Cesario scoring system

	Jacobs (1993)
Descriptive vividness	3
Methodological congruence	2
Analytical Preciseness	3
Theoretical connectedness	3
Heuristic relevance	3
Total	**14**
Level of evidence assigned	**QI**

The four quantitative studies were evaluated and assigned a level of evidence according to Oxford Centre for Evidence-based Medicine – Levels of Evidence. [7] Of those, the three case-control studies were assigned a level 3b, and the one

[7] Produced by Bob Phillips, Chris Ball, Dave Sackett, Doug Badenoch, Sharon Straus, Brian Haynes, Martin Dawes since November 1998. Updated by Jeremy Howick March 2009. Available: http://www.cebm.net/oxford-centre-evidence-based-medicine-levels-evidence-march-2009/

experimental paper was assigned a level 2b. The remaining paper was a mixed methods case study. It was evaluated against the criteria of the MMAT regarding the qualitative, quantitative and mixed methods components of the study. The study was assigned 75% (***). Table 3-4 has a summary of evidence using all three evaluation tools.

Themes

Three main themes emerged from the literature search - theory building and guidelines for practice regarding self-awareness following TBI in childhood; assessment of children following TBI; and interventions to improve self-awareness following TBI in childhood.

Theory building –In two of the three theory-building papers the authors started with the premise of adult models (Marcantuono and Prigatano, 2008) and conceptualised their utility with a younger population. Marcantuono and Prigatano (2008) utilized the holistic brain injury rehabilitation program (Ben-Yishay and Diller, 1990) and described 15 different groups that the children participated in over the week. The therapeutic day was 5-1/2-hour groups per day and the programme was tailored to the child's goals. Each element of the program was clearly described and had been adapted to the needs of children in general. Insights from learning theories were incorporated into the model of care. However, the programme was not differentiated for different developmental stages and there was a broad inclusion criterion by age (6-21 years). While the authors detailed the outcomes that could be monitored, they have no data to support the efficacy of the

model as yet and the strict inclusion criteria to the programme suggest that the results may not be generalizable across settings.

Gracey et al (2010) also suggested the application of an adult model to a younger population, These authors described an adapted version of the holistic neuropsychological rehabilitation (HNR) model (Cicerone et al., 2006). The authors outlined visually how the existing framework could be integrated conceptually and proposed a developmental framework for HNR. These authors differentiated between adults, children and adolescents but acknowledged that the framework was not tailored to developmental processes. Again they have not evaluated the programme that they have developed from this theoretical framework. This source is a poster presentation at a conference and has not been published as a full peer-reviewed article. There was not sufficient detail in the abstract or the poster to fully evaluate the robustness of the proposed concepts.

In both cases the focus of the theoretical model was on adjustment and adaptation following traumatic brain injury. The authors made adaptations to these adult models to accommodate the unique differences in childhood. Marcantuono and Prigatano (2008) stressed that children are developing self-identity at the time of their injury and would need particular guidance to develop a realistic view of who they are and how their injury may have affected them. As previously noted, it may not be until individuals reach adulthood that self-identity becomes fully established. The authors promote the use of less complex language, increased therapeutic support and the setting of age-appropriate goals. As we see, an attempt has been made to conceptualise self-awareness in children differently to adults. However,

there is a tendency to group all children together rather than separating out the developmental needs at different ages. There seems to be insufficient acknowledgement of typical development in these two papers.

In the third paper, Stuss and Anderson (2004) acknowledged unique differences in childhood from the perspective of biological change and skills development, as well as a psychological standpoint. The hierarchical model proposed by Stuss, Picton and Alexander and summarised in this paper focuses on brain regions, particularly the frontal lobes (Stuss et al., 2001). Stuss and Anderson (2004) considered in detail the biological maturation of the brain and reflected that regional areas may not be as hard wired in the immature brain. They unpicked more systematically the maturational aspects of child development and considered the impact of brain injury at different ages and stages of development. They productively proposed that it may be more beneficial to provide a more integrated conceptualization of adult and child theory and consequently promoted a comprehensive framework that will inform future research.

Theoretical considerations are also mentioned in two of the other papers (Jacobs, 1993, Viguier et al., 2001). These authors used observations and qualitative data to highlight theoretical and conceptual issues of self-awareness. Jacobs (1993) carried out in-depth interviews with ten children and ascertained that the children lacked knowledge – both of the injury itself and the consequences. Only one of the ten subjects had knowledge of how the brain works, what had happened to them and the consequences of brain injury on function. Jacobs noted that some areas of

difficulty were more easily recognised, particularly those that were concrete and observable, especially physical problems,

Viguer (2001) reported the results of a large, multi-centre group (*n*=186) of young people with and without Traumatic Brain Injury (TBI). They all completed a long questionnaire (149-item) that addressed medical issues, schooling and areas of psychosocial functioning. Again, it was noted that the young people with TBI had more difficulty recognising difficulties in behaviour and cognition when compared to clinician report. These findings endorse the adult findings that self-awareness is easier in the physical domain and more challenging in other less observable domains such as social and behavioural (Dirette and Plaisier, 2007).

While these authors identified the complexity and multi-facetted nature of self-awareness in children, they do not draw any conclusions about the important developmental issue of the child's level of knowledge related to their age at injury.

Assessments – only one assessment that has been designed to measure self-awareness for children with an acquired brain injury was identified in the literature review (Beardmore et al., 1999). Three further studies reported on self-awareness within the context of specific functional domains (Josman et al 2000 a and b; Zlotnic et al 2009).

Beardmore and colleagues developed the Knowledge Interview for Children (KIC) from the findings of the previous study, Jacobs (1993), that highlighted the lack of knowledge that children with TBI have about their injury. Having established that children and young people lacked knowledge of brain injury in general, and their

own injury and consequences specifically this study aimed to increase their knowledge. The assessment measure was developed as an outcome measure of the education programme. There were two sections of questions. Section A concerned Knowledge of TBI (12 items) and Section B was an Awareness of Deficit checklist (10 items). The items were adapted from a checklist used with adults with brain injury. It is encouraging to have a psychometrically tested assessment measure that is specifically designed for children following brain injury. The intervention study is reported below.

Zlotnic and colleagues reported two case studies that were used to examine the effectiveness of an intervention protocol. They used a specific measure of self-awareness that was only concerned with mobility. The Awareness of Mobility Deficits Questionnaire was designed for the purposes of the study. The questionnaire has three items and the participant and the clinician rate performance. A discrepancy score is calculated of the difference between the two raters. Unfortunately, little information was available about the psychometric properties within the paper, or on further searching.

Two case control studies were reported by Josman and colleagues (2000 a and b). One assessed memory, and the other categorisation skills in a group of children with brain injury, compared to a control group. In both cases, the authors described an awareness component in the assessments that are used in the research. The Contextual Memory Test and the Toglia Categorisation Assessment asked the children to rate their general awareness, self-prediction and self-estimation. In both cases, the self-awareness scores were significantly correlated

with performance scores. The same format was used in both assessments and it is possible that these questions about knowledge, prediction and evaluation could be used in other domains, such as communication and school performance.

Interventions – two studies were sourced that reported on intervention to improve self-awareness. They included a before and after measurement of self-awareness (Zlotnic, 2009; Beardmore et al 1999).

Zlotnic et al (2009) reported on two case studies in relation to the dynamic interaction model of self-awareness (Toglia 2005). Joint goals were set that included functional skills such as handwriting and mobility. Self-awareness training included direct feedback, encouraging self-evaluation, providing cues and discussing situations when deficits may interfere with functional performance. At times the feedback was concrete and focussed on motor activities (case 2). Self-rating and therapist ratings were compared throughout the programme. The therapist and participant ratings were more closely aligned at the end of the intervention in handwriting and mobility.

These results have to be viewed with caution however, when considered with reference to a paper in the adult literature that discussed measuring change in self-awareness (Sherer et al., 2003). When there are actual changes in the individual's functional performance, there is less scope to over-estimate their performance and thus there will be less discrepancy between the raters that is not related to self-awareness.

One small experimental study of self-awareness following TBI in children was identified in the literature (Beardmore et al., 1999). The authors premise was that the children lacked knowledge of brain injury generally, and also specifically about their own injury, and that their self-awareness would increase if they had greater knowledge. Twenty-one children with TBI were assigned to 2 groups and they either received one injury education or study skills information session and some homework to complete over the coming month. They were reassessed on a second visit. Although it is encouraging to have an intervention study in this under-researched area, the findings are limited due to the small sample size and the short term nature of the intervention and review programme.

Table 3-4: Summary of literature sourced in search strategy

Study	Methods	Subjects	Findings	Level of evidence		
				Oxford EBM	Cesario	MMAT
Limited Understanding of Deficit in Children with Brain Dysfunction (Jacobs, 1993)	Exploratory multiple case study	n=10, age 7-15 yrs	All children had limited understanding of their condition with more awareness of physical aspects of disability		QI	
Does Information and Feedback Improve Children's Knowledge and Awareness of Deficits after traumatic Brain Injury (Beardmore et al., 1999)	Experimental	n=21, age 9-16 yrs	Subjects had poor understanding of TBI and some had unawareness of deficits but not helped by intervention programme	2b		
Performance of	Case control	n=30,	Brain injury group scored lower in memory			

Children With and Without Traumatic Brain Injury on the Contextual Memory Test (Josman et al., 2000b)		age 8-14yrs, severe TBI + 30 controls	assessment. Self-awareness scores correlated to performance scores	3b		
Evaluating Categorization Skills in Children Following Severe Brain Injury (Josman and Jarus, 2001)	Case control	n=30, age 8-14yrs severe TBI +30 controls	Brain injury group scored lower in cognitive assessment. Self-awareness scores correlated to performance scores	3b		
A psychological assessment of adolescent and young adult inpatients after traumatic brain injury	Case control	n=186; TBI=83 and non-TBI=103 age 14-25 yrs	Different levels of awareness in different domains. Poorer self-awareness in cognitive and behavioural domains. Also explored relationship between self-awareness and anxiety/depression	3b		

(Viguier et al., 2001)						
Use of the dynamic interactional model in self care and motor intervention after traumatic brain injury: explanatory case studies (Zlotnic et al., 2009)	Mixed methods case study	n=2, age 16, 17 yrs	Improved awareness in mobility and writing domains following Toglia adult model of intervention (Toglia and Kirk, 2000)			75%(***)
The frontal lobes and theory of mind: Developmental concepts from adult focal lesion research (Stuss and Anderson, 2004)	Theory	n/a	Proposition of a hierarchical model of consciousness that includes injury and developmental influences	N/A		
A holistic brain injury rehabilitation	Guidelines for practice	n/a	Proposition of a multidisciplinary programme of intervention with explicit aim of	N/A		

program for school-age children (Marcantuono and Prigatano, 2008)			developing awareness of deficits			
Holistic rehabilitation in the developmental context (Gracey et al., 2010)	Guidelines for practice	n/a	Proposition of an integrated model of psychosocial adjustment and development following ABI	N/A		

This search yielded a disappointing number of articles relating to a potentially important area of occupational therapy practice. However, it is encouraging that the quality of the evidence is high. From a theoretical perspective, clinicians working with children and young people following TBI have little information to guide their practice and will be tempted to rely on the adult literature. Some authors have attempted to increase the evidence base by using an adult model and considering its utility with a younger age group (Marcantuono and Prigatano, 2008, Gracey et al., 2010). In the earlier case, the authors acknowledge that this is not an ideal situation as the young people are still in a period of development when they have their injury and may not be directly comparable to the adult population. Other authors (Stuss and Anderson) propose a preferable situation that integrates adult and child theory in order to increase understanding of the complexity of impaired self-awareness following a brain injury in childhood.

It is encouraging that Tonks and his colleagues provide an excellent worked example of how a developmentally driven approach can be applied to one particular area of interest following brain injury in childhood (Tonks et al., 2009). Emotion and empathy skills are explored following a brain injury in childhood. The key to the success of this work is that the authors explicitly set out to explore social competence as it develops in childhood and how a brain injury will affect the expression and/ or development of these skills. They highlight the importance of taking a temporal perspective in childhood i.e. change over time, and the importance of considering the maturation of children from a physiological as well as

a cognitive and social dimension. An integrated approach such as this should inform the methodical choices made in this study.

3.3 Chapter Summary

This literature review has produced a limited amount of literature relating to self-awareness following a brain injury in childhood. It is clear that this is an area of clinical research that is still in its infancy. The theoretical formulation is incomplete and is overly reliant on the adult models of self-awareness. Measures of self-awareness are sparse and lack rigorous testing and interventions to address deficits in self-awareness have not been well described and evaluated as yet.

The research that is described in the remainder of this thesis is a clinically-based study which addresses the question of how different self-awareness following a brain injury in childhood is from that experienced in adults. It is hoped that the results will inform clinicians in paediatric brain injury rehabilitation settings and guide occupational therapists in their role with this client group.

The aims, objectives and research questions are outlined below:

3.4 Aims of the research

Aim

To gather quantitative and qualitative longitudinal data from children and young people who have experienced a moderate to severe traumatic brain injury in order to understand their level of self-awareness.

Objectives

1. Explore the profile of self-awareness following moderate to severe TBI in childhood
2. Compare the profile to typically developing children as reported in the literature
3. Explore the profile of the ongoing development of self-awareness following TBI in childhood
4. Compare the ongoing profile to typically developing children as reported in the literature

Research questions

What is the level of self-awareness in school age children who have suffered a moderate to severe traumatic brain injury?

How does the level of self-awareness following a TBI in childhood compare to typically developing children?

How does the ongoing development of self-awareness following a TBI in childhood compare to typically developing children?

What is the impact of injury variables and post-injury presentation on self-awareness following a brain injury in childhood?

4 Chapter 4: Methodology

4.1 Chapter overview

This chapter outlines the research study that was designed in order to address the aims outlined at the end of the previous chapter. The scientific and personal rationales are explained and then the research design and methods are explained. The collection and analysis of the data will be described and the ethical issues will be highlighted towards the end of the chapter. Throughout this chapter I hope to convey some maturity and honesty as a researcher as I explain my personal motivations for carrying out this research.

4.2 Rationale

4.2.1 Scientific rationale

As highlighted in the previous chapters, there is currently no theoretical model to accommodate the phenomenon of self-awareness in childhood following a brain injury. While there is a growing body of evidence regarding some of the consequences of TBI in childhood, self-awareness is one of a number of clinically important areas that lack empirical guidance.

Therefore the research context of this study was theory building. In order to explore self-awareness in childhood following a TBI, an attempt to observe the phenomena was required. However, a pure inductive approach to theory building would have been naive for two main reasons. First, some knowledge of the phenomenon already existed and was accessible to the researcher. As theoretical construction had already been proposed and child development, neuroscience and

adult neuropsychology models of self-awareness already existed, it would have been impossible for the researcher to make independent observations. Deductive reasoning would necessarily have followed as the new observations were being made in the context of existing knowledge.

Second, to explore the unique experience of the child, a more phenomenological approach was necessary. Children are dynamic and complex individuals and the impact of a brain injury on a child would result in a unique experience.

As a result, a holistic model of observation that included the child's illness experience underpinned this research. The child's experience was explored within the context of both their wider phenomenological experience and their ongoing development.

The methods included semi-structured interviews in addition to self-report measures that have developmental norms associated with them. The results were compared to existing models and new theoretical modelling was proposed.

4.2.2 **Motivation**

My motivation to conduct this research was a clinical one. Some of the children and young people who received in-patient rehabilitation were reluctant to address their difficulties following their brain injury and this affected their ongoing engagement in rehabilitation. They wanted to go back to school, friends and other childhood occupations without making any accommodations for their newly acquired difficulties. In many cases they did not appreciate that their participation in everyday occupations would be affected and did not see that there would be a

problem. They were not readily using strategies for support, such as planning sheets and visual timetables to help them to organise their school day. Neither were they readily using equipment, such as non-slip mats, that could assist with their motor difficulties.

The clinical team agreed that this situation caused a concern and started to carry out interventions aimed at developing the children and young people's awareness of their difficulties. The children had "brain" projects, made leaflets to share at school, prepared scripts to use at school, and looked up brain education websites. I also used "goal/plan/do/review" (Ylvisaker, 1998a page 244) worksheets with explicit feedback to the children and young people during occupational therapy tasks such as cooking and shopping but there was not a strategic intervention plan that was related to their age. I developed a particular manner of speaking to the children during activities that provided constant verbal feedback on the occupational performance. Knowledge of how to do this type of intervention was taken directly from the adult literature that, as previously highlighted, described the same issue regarding engagement in rehabilitation and thus poor long-term recovery outcomes in the adult setting.

However, after a time, I began to question the validity of this intervention in the light of my own experiences as a parent. I had seen at first hand the maturational aspect of self-awareness in my own children. My son, at age 11 years, was asked what he might be when he grew up. He answered that he may still think about being a professional football player even though he did not enjoy competitive sport and did not like the competitive element of playing football at a local boys' club. In

contrast to this commonplace expression of typical development, we had some expectations of children as young as 8 years old in the clinical setting to be addressing issues of self-awareness following a traumatic brain injury.

On the other hand, there were some more cautious clinicians in the team who raised concerns about the ability of a child to be involved in self-awareness intervention at all. The concern was that the children were in a fragile state following the traumatic nature of the events that had occurred. Perhaps they did not yet have the resources to make progress in the area of self-awareness in the rehabilitation setting.

In light of these observations I became motivated to fully investigate the issue of self-awareness in the context of child development. The need to embrace both a subjective and objective position was necessary so that the developmental issues could be highlighted in the context of the child's real experience.

I was motivated to improve our own service delivery model and inform other rehabilitation services. I aspired to have the knowledge to work with colleagues to develop an age-related programme of intervention that clinicians could confidently deliver to children and young people following a traumatic brain injury.

4.3 Research design

4.3.1 Research assumptions

A number of assumptions were made within this research study. One assumption was that the measurement of self-awareness could be carried out in a similar way as the adult studies. In traditional self-awareness studies in adults, the primary

means of measurement is a discrepancy value derived from a difference between the self-report and other-report. In these studies it is be presumed that a discrepancy between self and other-report is a reflection of the individual's impaired self-awareness. A similar model was used in the current study with parents, teachers and therapist providing the "other" report. As self-awareness is an internal construct, there was an assumption that self-report measures could capture the child'/young person's perception. The interview would provide an opportunity to probe further, and indeed the format of the self-understanding interview promotes probing with further questions such as "and what does that mean?" and "and is that important?" "Why?" until the child/young person has nothing more to add and says something like "it just is" or "I don't know". The other self-report measures include statements of behaviours such as "I am kind and helpful" "I always think before I act" and the level of agreement that a child/young person reports about these statements can be validated by others who have observed the behaviours.

Children and young people who have sustained a TBI are likely to have some communication difficulties either at an expressive level (being able to say the words) or at a cognitive level (being able to construct the ideas to say). It was assumed that my clinical expertise would help in this area. I would be able to paraphrase if required and I am used to speaking to children who use a communication aid.

There is a great deal of individual difference in the general population. However, there is also a great deal of similarity and theories of child development exist

through decades of thorough scientific investigation. It is assumed that the maturational process is correct and that the development of self-awareness over childhood can be trusted. It was assumed that the measures chosen from typical development would have some norms from a typically developing population that would be used as a comparison.

4.3.2 Case study approach

The case study approach is not new to science. It has its roots in the inductive observation of the early philosophers and then was subsequently expanded by John Stuart Mills in the 19th century. Mills proposed that the evidence from individual cases contributed significantly to the scientific building of theory. He posed two canons, namely the "Method of Agreement" and the "Method of Disagreement" that have continued to influence the development of theory building through case study research (George and Bennett, 2005). Case study research is widely used in a variety of academic research. In each setting the term case can have a different meaning. For example, in education research the case may be a school, and in business research the case may be a financial institution. In this research study, a "case" was an individual child or young person.

Case study research is advantageous for the detailed examination of complex phenomena. Self-awareness following a brain injury is one such complex concept that is of interest to many clinicians including nurses, doctors, therapists and neuropsychologists. Neuropsychologists and doctors have a long tradition of using case studies to develop theoretical constructs. Famously, the case study of Phineas Gage led to a greater understanding of the higher cognitive functions of the frontal

lobes and remains a major influence of theoretical construction (Macmillan, 2002, Goldberg, 2001).

Case study research is also valuable for heterogeneous populations. Children and young people who have sustained a brain injury are a heterogeneous group. Despite having the same diagnosis of brain injury or indeed the subgroup of traumatic brain injury, the mechanism of injury alone makes every case different. For example, a child who collides with a football post while running (at a few miles per hour) will have a different pathology to an unrestrained car passenger in a high speed road traffic collision or a speed boat accident. Apart from the collision speed there will be different forces of rotation and damage to the skull. In addition to the injury itself, the children and young people will be at different ages and different stages of development. They will also have had different life experiences and styles of parenting and schooling. However, this is a clinical research study and controlling for all the variables or even a number of them would reduce the clinical utility of the findings. A case study approach allowed me to gain breadth and depth to each case, permitting a full investigation of all the factors that may be relevant and different to that which we already know about adults (Yin, 2009).

When case study research is carried out with a heterogeneous population, there is concern that it will lack external validity. However, this is less of a concern here as the children and young people will be recruited from the clinical setting and the possible diversity of results may still have clinical importance.

4.3.3 Multiple case study approach

Yin (2009) strongly supports the power of the multiple case study approach and goes as far as to suggest that replicating case studies has similar power to replicating experimental studies. Multiple case studies can be used to support generalisation if two or more case studies support a proposed theory. In this research study the inclusion and exclusion criteria were used to obtain a set of cases that had some similar features. Having some features in common would give weight to any findings that were similar across the set of cases.

4.3.4 Longitudinal case study

The aim of the study was to investigate self-awareness within the context of a developmental framework. A fundamental characteristic of development is the concept of change over time. In the planning of the study it was a key element to not only understand the change over time in typically developing children from the literature, but additionally to consider the unique difference that a traumatic brain injury had made to the ongoing self-development of children.

Attrition is a common challenge to longitudinal research. The importance of staying in the study for the duration of the data collection was stressed to the participants during the recruitment phase of the study. I took additional steps to keep the participants in the study. Birthday cards and Christmas cards were sent to the participants. Furthermore, I was mindful to thank the participants and their families at every opportunity for their ongoing involvement in the study. I had occasion to email the young people and their parents from time to time and I always added an additional thanks to my email replies. Fortunately, the case study design is more accommodating of subject attrition than a group study that aims for

a complete data set from a pre-calculated number of participants, so any loss to follow up did not have a terminal effect on the study. In fact, the reasons for dropping out provided additional information to consider in the analysis of results and recommendations.

4.3.5 Mixed methods

The tradition of mixed methods in health research has gathered momentum in recent years. Mixed methods research involves combining some components of qualitative and quantitative methodology to a greater or lesser degree and at some or all of the stages in the research process (Morse and Niehaus, 2009, Bryman, 2006a, Creswell, 2009). In the last decade there has been an acceptance that the two methodologies can be complementary and indeed that the combination can lead to a methodology that makes the best of both approaches (Bryman, 2006b, O'Cathain et al., 2010). There has been an increase in the number of published mixed methods studies and there is now a journal dedicated to this methodology[8].

As an occupational therapist, this type of methodology is rather intuitive as it parallels the assessment process in clinical practice. The College of Occupational Therapists describe clinical assessment as

> *A process of collecting and interpreting information about people's functions and environments, using observation, testing and measurement, in order to inform decision-making and to monitor change.* (College of Occupational Therapists, 2010)

[8] Journal of Mixed Methods Research has been published quarterly since 2007 http://mmr.sagepub.com/

Standardised assessment instruments are used routinely in clinical practice and the therapist derives a numeric score. Additionally, therapists gather qualitative information from clinical observations in real life settings. While some therapists carry out occupation-based observations first and utilise standardised assessments to confirm hypotheses, other therapists administer standardised assessments first. Regardless of the order of events, few would argue that each complements the other and gives breadth and depth to clinical assessment.

This study used mixed methodology to gain insights from both quantitative and qualitative research methods, acknowledging that no one method is sufficient when investigating complex phenomena, such as self-awareness (Morse and Niehaus, 2009, Bowling, 2002). The intention was to integrate the quantitative data with the interpretive findings from qualitative methods to obtain a richer and stronger array of evidence from the research participants (Yin, 2009).

There are a number of mixed methods designs that are described in relation to pacing, instrumentation and point of interface (Bryman, 2006b, Creswell, 2009). The mixed methods model for this research study is outlined in Table 4-1. It was a QUAN+QUAL design, demonstrating that each of the data had equal weighting and importance, a concurrent pacing indicating that the data was collected at the same time, and a fully integrated interface meaning that the whole study had a mixed method design, not just the analysis.

Table 4-1: Mixed methods model

Mixed methods model	
Design **Theoretical drive: inductive/deductive** **QUAN+QUAL**	**Pacing**: concurrent
QUAN component**:** **Harter scales** **SDQ**	**QUAL component**: Self-Understanding Interview KIC
Point of interface**: fully integrated**	

4.4 Participants

4.4.1 Selection

The participants were selected from children and young people who had accessed the brain injury services of one specialist UK brain injury centre for children (see Figure 4-1). Details of all children who had accessed the services in the last 5 years were examined to ascertain whether they met the following criteria:

Inclusion criteria

Diagnosis of Traumatic Brain Injury

1-5 years post-injury

Age 4-18yrs at time of injury

Parents of TBI participants

Current teachers of TBI participants

Exclusion criteria

Premorbid history of mental health condition or learning disability – confirmed by clinical team or parents

Insufficient cognition or communication to complete self-rating scale or interview – confirmed by researchers' clinical experience and confirmed by clinical team if necessary

Over 18 years who are unable to consent

Further control of variables was not indicated as this was a descriptive study with clinical relevance and as such it should represent the varied presentation of the clinical population.

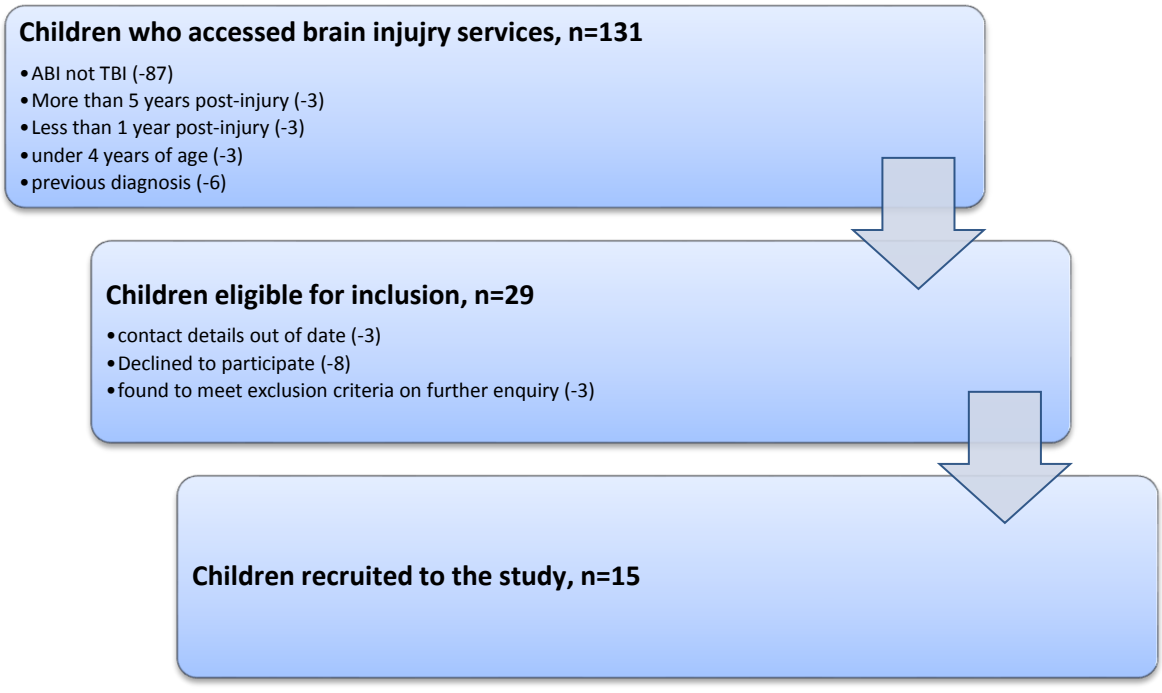

Figure 4-1: Selection using inclusion and exclusion criteria

4.4.2 Recruitment

All of the recruitment took place from one specialist brain injury centre, The Children's Trust, Tadworth. All of the children and young people had accessed brain injury services at The Children's Trust in the past five years and were now either living at home, university or were receiving further rehabilitation services elsewhere. The recruitment was a two-stage process. Firstly, the Chief Executive wrote to the potential participants informing them that The Children's Trust was supporting the research project and that they could expect me to approach (see Appendix 2). They were instructed to opt out at this stage if they were not interested. Secondly, I wrote to the potential participants and their families with the information sheets and consent forms suitable for their age (see Appendix 3,4,5). Again, they were instructed to opt out at this stage if they or their child did not feel able to participate. Twenty-nine children and young people met the inclusion criteria and were approached for inclusion in the project. Consent was taken in person at the first visit, after the children, young people and parents had the opportunity to ask any questions of clarification.

Fifteen children and young people were finally recruited to the study. I was unable to recruit the other fourteen as their contact details were out of date (n=3), they declined to participate (n=8) or they met the exclusion criteria on further examination (n=3).

4.5 Data collection methods

Having established the need to take a developmental perspective in this study, it was essential to seek out instruments that had been used with typically developing

children over a number of years in addition to newly developed measures that have been used with children following brain injury. The instruments included self-report measures, semi-structured and structured interview, and direct observation task with feedback tool (see Table 4-3). All of the self-report measures that were chosen for this study had a parallel version that could be completed by another with knowledge of the child/young person (teacher, parent or researcher) for triangulation of data. Additionally, there would be comparison data to calculate discrepancy scores (see section 4.5.7 below). Discrepancy scores are commonly reported in the literature as a measure of self-awareness.

The data collection as mentioned above was concurrent, and qualitative and quantitative data were collected at the same time where possible.

4.5.1 Self-report measures

Self-Perception Profile for Children (Harter, 1982)

The Self-Perception Profile for Children (SPPC) is a self-report measure for children age 7-11 years (see Appendix 13.6). The scale was developed with the aim of capturing the multifaceted construct of self in child development (Harter, 1982). There are six subscales with six items in each - scholastic competence, social acceptance, athletic competence, physical appearance, behavioural conduct and global self-worth. One of the distinguishing features of the SPPC is that global self-worth is measured as a distinct and separate construct rather than being the sum of the other lower-order constructs. This is strength of the measure as it reflects the multifaceted concept of the self phenomena.

Each item presents two children who are different, e.g. “some kids often forget what they learn but some kids can remember things easily” and the respondent has to choose which child they are most like. The respondent is then asked to rate how alike they are – a little or a lot. The forced choice item format is designed to emphasise individual differences amongst children and legitimise the choice that respondents make. The forced choice format is particularly explicit and concrete, which is particularly helpful for children and young people who commonly experience cognitive difficulties following their brain injury. Harter (1982) reports the psychometric properties of the SPPC from large sample populations (see Table 4.3). She also describes a four factor model for the scale - cognitive competence, physical competence, social competence and general self-worth. The four factor model has continued to be the subject of debate in the literature (Rose et al., 2011, Muris et al., 2003).

Scoring - Each of the 36 items is assigned a value of 1-4. A scoring template is available to assign the raw scores to each response (see Appendix 13.6.5). The raw scores are transferred onto a summary sheet that assigns the questions to each of the six domains. A mean score can then be derived for each of the six domains.

There is a teacher version of the SPPC that asks the teacher to rate the child’s performance across domains in the same format as the child version. There are 16 items in the teacher version and a mean score is again obtained.

Self-Perception Scale for Adolescents (Harter, 2012)

There is an upward extension of the SPPC, the Self-Perception Profile for Adolescents (SPPA) for young people aged 11-18 years (Harter, 2012b). It has 45 items covering eight domains that reflect the additional concepts of self in adolescence - scholastic competence, physical competence, job competence, behavioural conduct, social acceptance, physical appearance, romantic appeal and close friendship. The item layout and the scoring are the same as the SPPC. Both versions of the scales will be used in this study, depending on the age of the child. The term 'Harter Scales' will be used to refer to them collectively. There is a teacher version of the SPPA which also follows the same format. It has 16 items across the eight domains.

Although the Self-Perception Profile for Children was developed in the 1980s, the different versions of the scale have continued to be utilised in recent studies, both with typically developing children and those with a range of diagnoses (Lindsay and Dockrell, 2000a, Edwards et al., 2004)

Scoring – the scoring procedure is the same as the SPPC

Strengths and Difficulties Questionnaire (Goodman, 2001)

The Strengths and Difficulties Questionnaire (SDQ) is a one page questionnaire (see Appendix 13.7) to measure psychological adjustment in children and young people (Goodman, 2001). There is a parent and teacher version for children aged 3-11years and a self-report version for young people aged 11-17years. On-line

support for administration and reporting makes the measure easy for clinicians and researchers to access and use.

The scale covers a range of 25 positive and negative psychological attributes that are grouped into 5 sections – emotional symptoms, conduct problems, hyperactivity-inattention, peer problems and prosocial behaviour. The user is asked to rate the items on a 3-point Likert scale (0-2). Each domain yields a separate score of 0-10.

The SDQ has robust psychometric properties. Reliability and validity has been confirmed for UK population in a large scale study - 9,998 parents, 7,313 teachers and 3,983 11-15 year olds (Goodman, 2001). The five-factor model, internal consistency, interrater correlations and retest stability were all confirmed as predicted and to significant/satisfactory levels (see Table 4.3).

There is a parent version of the SDQ that asks the same questions in the third person. This version also yields a score of 1-10 in each domain.

The SDQ has been used in recent paediatric brain injury studies to examine the relationship between brain injury and both the global and more specific outcomes such as facial expression disturbance (Levac et al., 2008, Tonks et al., 2007b).

Scoring – an online calculator can be used to obtain scores for the SDQ (http://www.sdqscore.org/Amber). A report is generated that provides the raw scores and the banded score (close to average, slightly raised, high or very high) in six domains – overall stress, emotional distress, behavioural difficulties,

hyperactivity and attentional difficulties, difficulties getting along with other children, kind and helpful behaviour. The parent report is scored in the same way.

4.5.2 Semi-structured Interview

Self-Understanding Interview (Damon & Hart 1988)

The Self-understanding Interview (SUI) is a semi-structured interview for children and young people (see Appendix 13.8) aged 6+ years with seven items derived from Damon & Hart's developmental model of self-understanding – self-definition, self-evaluation, self in past and future, self-interest, continuity, agency and distinctness (Damon and Hart, 1988).

The main questions in each of the seven categories are presented e.g. "what are you like? What kind of person are you?"; and then the interviewer probes the participant with further questions such as "what does that say about you? Is that important? Why is that important?" until that item is 'exhausted', either by the subject repeating himself or answering a final comment such as "because it is". The level of response fits within Damon and Hart's hierarchical model and reflects increasing development stages of self-understanding (Damon & Hart 1988).

Internal consistency and test-retest reliability scores are reported (see Table 4.3). Reliability score for what is a scoreable "chunk", in addition to weighted average and best level score, all range from 0.62 to 0.79. While test-retest reliability of weighted averages is reported as r=0.49, 64 % of the subjects had the same level at the two testing times. Damon & Hart (1988) defend these levels as acceptable for a developmental measure where some change can be anticipated.

The Self-understanding Interview has been utilised in recent research for primary school age children. The multi-dimensional construct of the measure enabled researchers to identify particular domain-specific issues in their populations (Farley et al., 2010, Malti, 2006).

Scoring - The responses to the SUI are analysed numerically. The interview transcript is examined for text data that could be scored as "chunks". Chunks are pieces of conversation that answer, and then elaborate on, the interview question. A chunk contains all of the related conversation until the child has nothing more to say on that question and says something like "I don't know" or "that's it". The identified chunk is then assigned to one of seven domains (physical, active, social, psychological, agency, continuity and distinctiveness), and then assigned a score of one to four, to reflect the complexity of the narrative. Examples are given in the scoring manual. These can be used to derive a 'best level' score and a 'weighted mean'. The text data was subsequently available for qualitative analysis (see Section 4.6.3 below).

Knowledge Interview for Children (Beardmore et al 1999)

The Knowledge Interview for Children (KIC) is a little known structured interview for children with a traumatic brain injury (see Appendix 13.9). It was developed and used in a single study in Australia with a group of 21 participants aged 9-16 years (Beardmore et al., 1999). It was developed in response to a previous study that highlighted a lack of knowledge in children with TBI surrounding their injury (Jacobs, 1993). It has a section of questions about brain injury knowledge. The

child/young person is asked about their accident and what they can remember. They are asked some questions about terminology such as brain injury and coma, and they are asked about their knowledge of the brain and how it works. They are then asked about the general long term consequences of a brain injury, before being questioned directly about themselves. They are asked directly if they have problems in a range of areas such as getting tired easily, keeping up with the rest of the class, writing, feelings and behaviours.

Although this measure has limited psychometric properties, it is the only measure that has been developed for this particular client group and purports to measure self-awareness. KIC has construct validity as a measure of self-awareness as the theoretical construct and the items it purports to measure are comparable to adult measures of self-awareness. Inter-rater reliability and internal consistency for 'Knowledge of TBI' were reported to be very good within the constraints of this small study (see Table 4.3).

Scoring – A scoring guide was obtained from the primary author (see Appendix). The participants' answers are assigned a 0 (incorrect/don't know), 1 (partially correct) or 2 (adequate answer) according to the guide and a total raw score is obtained. An Awareness Discrepancy Index is derived when the child/young person's score is compared to the parents' score, who completed a parallel version. A discrepancy is scored when a parent identifies a problem that is not endorsed by the child/young person. The maximum discrepancy score is 12. A higher score equates to poorer awareness.

4.5.3 Direct observation of functional task and self-rating of occupational performance

Cooking task and executive function map (see Appendix 13.10 and 13.11)

The Children's Cooking Task was delivered in conjunction with a self-evaluation tool (executive function map). The Children's Cooking Task (hereafter to be referred to as Cooking Task) is a new version of the ecological assessment that has been developed for adults with a brain injury (Chevignard et al., 2008). The children's version has not yet completed its standardization process (Chevignard et al., 2009) but the authors gave permission for the measure to be used in this research (personal communication). Using this Children's Cooking Task ensured that all the participants carried out the same occupational performance task. The main aim was to have the opportunity to observe the participants' evaluation of occupational performance in the moment, also referred to as "live" or "on-line" in the literature (Dirette et al., 2008b, Toglia and Kirk, 2000).

The executive function map (Ylvisaker, 1998a) is a self-evaluation form that includes a 10-point Likert scale and supplemental questions. The executive function map and similar tools are commonly used in clinical practice and research to encourage self-reflection and evaluation as a suitable means of accessing attitudes, opinions and beliefs (Robson, 1993). Likert scales have received criticism as they produce ordinal data that has been historically held as unable to be analysed using parametric statistics. Recent debate has challenged this standpoint and endorses the use of parametric statistics with this type of data (Norman, 2010). In children's research, however, Likert scales have been shown to be helpful as they are easy to understand and use (van Laerhoven et al., 2004). In the current research study

some of the children and young people may even have been used to the executive function map while they received therapy services at The Children's Trust. Familiarity with this tool would not have been a concern as it is based on a general Likert style that they may also have seen at school.

Scoring

Cooking task - the raw scores were derived from a tally of errors observed by the researcher during the cooking task. Different types of errors were defined by the authors (Chevignard et al 2010) and a total of each type of error was captured in addition to a total overall errors (see Table 4-2).

Executive Function map - The participants were shown the cooking task, were given instructions and were then asked to predict their ability to complete the task. The executive function map has a 10-point Likert scale and the participants were additionally asked to predict the type of difficulties that they might encounter. If no reply was forthcoming, they were asked if they thought they may have for example physical or cognitive/thinking difficulties.

On completion of the task, the participants were asked again to numerically and descriptively review their performance. The researcher also rated their performance using the 10-point scale.

Table 4-2 Cooking task scoring form

Error	Description	Number of errors
Omission	Any action or sequence of actions necessary to reach the goal which is omitted or incompletely performed, such as forgetting an ingredient or an instruction stated in the recipe.	
Addition	Any action or sequence of actions unnecessary to the completion of the task, such as using distracter ingredients, opening the drawers or closets, picking up an object and putting it down without using it.	
Substitution-sequence error	Any action performed out of the appropriate temporal sequence or any object that is misused or inappropriate to the sub-goal, such as selecting the wrong recipe, putting a spoon covered in chocolate into the flour bag, or a salad bowl in the oven, or not following the order of ingredients incorporated in the recipe.	
Estimation error	Poor estimation of the quantity of ingredients, of the size of an object, of space or time, such as putting too much (or not enough)	

	sugar in the cake, placing the salad bowl on the cookbook, cooking the cake too much or not enough.	
Commentary-question	Any question, remark or joke to the examiners, although the subject had been clearly instructed to act as if he/she were alone, such as commenting on the weather, or asking how to perform an action, or where to find an ingredient or a utensil.	

Table 4-3: Properties of measures used in this study

Scale	Type of measure	Components of test	Scores derived	Psychometric properties
Self-perception Scale for Children (Harter, 1982)	Self-report measure	Scholastic competence Social acceptance Athletic competence Physical appearance Behavioural conduct Global self-worth	Mean scores	Internal consistency: *r*=0 .73-0.86 across scales Test-retest reliability: *r*=0 .69-0.87
Self-Perception Scale for Adolescents (Harter, **2012)**	Self-report measure	Scholastic competence Social competence Athletic competence Physical appearance Job competence	Mean scores	Internal consistency: r=0.74-0.93 across scales

		Romantic Appeal Behavioural conduct Close Friendship Global self-worth		
Self-Understanding Interview (Damon and Hart, 1988)	Semi-structured interview	Physical Active Social Psychological	Number of scoreable chunks Distribution of chunks across domains Weighted mean Best level score	Internal consistency: *r*=0.70 to 0.83. Test-retest reliability of weighted averages: *r*=0.49
Strengths and Differences	Self-report measure	Emotional symptoms Conduct problems	banded score (close to average, slightly raised,	Internal consistency: mean 0.73 Interrater correlations: significant at

Questionnaire (Goodman, 2001)		Hyperactivity/inattention Peer problems Prosocial behaviour	high or very high) in six domains – overall stress, emotional distress, behavioural difficulties, hyperactivity and attentional difficulties, difficulties getting along with other children, kind and helpful behaviour	*p*<.001 Test retest reliability: *r*= 0.51-0.73
Knowledge Interview for Children (Beardmore et al., 1999)	Structured Interview	Knowledge of accident Knowledge of brain function Knowledge of general	Awareness Discrepancy Index Qualitative data	Knowledge of TBI Internal consistency: *r*= .75 Inter-rater reliability: *r*=.96

		difficulties after TBI Knowledge of personal difficulties following TBI		
Executive Function Map (Ylvisaker, 1998a)	Self-rating of occupational performance	Problems identified in any domain that may impact or have impacted on occupational performance	Self-rating score 1-10: before and after Therapist rating 1-10: after	Not available
Children's Cooking Task (Chevignard et al 2010)	Open-ended assessment of executive functions	Completion of 2 cooking tasks	Error scores Qualitative analysis	Internal consistency : *r*=0.86 Test-retest reliability : *r*=0.89

4.5.4 Collection of additional and comparative data

Comparative data - The parents and teachers supplied comparative data. The Harter Scales had been shown to be accessible to teachers in previous studies (Lindsay and Dockrell, 2000a). The teacher is able to report on several domains of function as observed across the school day. One assessment was considered to be an adequate burden for busy teachers. On the first visit the participants were asked to identify a teacher who would be able to answer questions about them. Following the first visit, the teacher version of the Harter Scales were sent by post to the named teacher with a covering letter, an information sheet, consent form and stamped addressed reply envelope.

The measures chosen for parent report were ones that had a parallel child and family version and could quickly and easily be completed, again to manage the assessment burden. The SDQ and KIC were selected to fit these criteria. On the first visit the parent was asked to complete the SDQ parent format and the KIC. In the majority of cases these were completed during the first visit. Where the parent was not present on the first visit, the questionnaires were sent to the parents with a covering letter, information sheet, consent form and stamped addressed reply envelope.

Additional data - as an exploratory research study it was inappropriate to determine variables a priori. Therefore a broad selection of data was collected from the family and the rehabilitation and medical reports (see Table 4.4). Field notes were taken on the data collection visits and added to the case presentations and analysis of variables where appropriate.

Table 4-4: Additional variables collected from family and records

Pre-injury variables	Injury variables	Post-injury variables
IQ if known, qualifications Socio-economic status (SES) Confirm no problems at school Confirm no premorbid medical concerns Confirm no significant trauma in childhood prior to TBI	Type of injury Severity of injury Glasgow Coma Scale Score (GCS) Scan data e.g. MRI/CT Medical complications Length of coma Length of Post Traumatic Amnesia Time to follow command[9]	Length of hospital stay Length of rehabilitation Rehabilitation outcomes Life changes – school, home, family Legal case pending

Socio-economic status of the participants was presented as an Index of Multiple Deprivation (IMD) score-2010 (Government, 2010). The IMD score is a combination of seven transformed domain scores, using the following weights: Income (22.5%), Employment (22.5%), Health and Disability (13.5%), Education, Skills and Training (13.5%), Barriers to Housing and Services (9.3%), Crime (9.3%), Living Environment (9.3%). The IMD score was calculated for each participant using their postcode.

4.5.5 Longitudinal approach – schedule

There were four data collection points over a two year period, with visits every six months (see Table 4-5).

The main data collection was during the first visit (T1) when the parent and teacher versions of the measures were also administered. The interview and self-report measures were repeated at the second and fourth visits (T2 and T4). Management

[9] Time to follow commands is sometimes used in reports to indicate the number of days before a patient is able to follow verbal commands, such as lift your arm, close your eyes. It can be seen as a measure of severity of brain injury

of four rounds of interview data may have been beyond the scope of a single researcher and so the interview was not repeated at third visit (T3). However, a direct observation of a functional task was carried out at this visit (T3). Prior to beginning the task, the participant estimated their level of competence and indicated what sort of difficulties they anticipated i.e. physical, cognitive. Following the observation the therapist and participant completed an evaluation of the task performance and again indicated what type of difficulties they had encountered.

Table 4-5: Longitudinal data collection schedule

	T1	T2 (T1+6months)	T3 (T1+12months)	T4 (T1+18months)
Participant	Harter scales SDQ Self Understanding Interview (SUI) KIC	Harter scales SDQ SUI KIC	Harter scales SDQ Cooking Task Executive function map	Harter scales SDQ SUI KIC
Parent	SDQ – parent version KIC			
Teacher	Harter scale – teacher version			

4.5.6 General format of data collection visits

- At the beginning of visit (with the exception of the first visit when consent was obtained)
    - Catch up on news from the last 6 months including – changes to school, teachers, relationships, living/social circumstances, achievements, medical updates etc.
- Complete Harter Scales

- Conduct interview using KIC and SUI interview schedules*
    - Researcher asked participant if they wanted to do SUI or KIC first "I'm going to ask you 2 sets of questions. One is like the questions you have just answered and the other is about your accident. Which questions would you like to do first?" If parents were present at this point the participant was asked if it was ok or would they rather the parent/family members left the room. The researcher explained about the recording device and set it up.

*on visit 3 Harter Scales were completed as usual and then the Cooking Task was introduced. Self-rating of the Executive Function Map was completed by the participant, the cooking task was completed, and then the ratings from the Cooking Task were completed by the participant and the researcher.

4.6 Data analysis methods

4.6.1 Reflexivity

It is important to recognise the impact of the researcher, particularly when it comes to data analysis. As I approached this study I was aware of a strong reflector trait in my personal profile and so I was easily able to recognise all of my preconceived notions. My own status as a professional and a parent had a bearing on how I approached this research.

First, I came to this research as an occupational therapist. I qualified as an occupational therapist 28 years ago. I had worked in the clinical area of acquired brain injury in a number of settings including acute hospital setting, rehabilitation,

and community settings, initially with adults for 10 years and more latterly with children for 15 years. I had experiences of children and young people overestimating their abilities and having difficulty setting realistic rehabilitation goals.

Second, I was influenced by my own experience as a parent. I have two children who are now in late adolescence and early adulthood. I had observed them evaluate their own abilities and set goals for their future and I was aware of how incomplete their sense of self was at times. These observations led me to reflect on some clinical situations when I possibly had unrealistic expectations of children's ability to reflect and set goals in the rehabilitation setting following their brain injury.

I had become more curious about self-awareness in childhood, both with and without a brain injury. Although I appreciated the multiple emotional, psychological and environmental factors that can affect the development of self, I had to be aware that I held a belief that it was the cognitive component of the ability to self-reflect and be aware of one's strengths and limitations that was the main factor.

I was aware that I had to be cautious of the impact of these beliefs on the collection and interpretation of the data. I was aware that I could have overlooked pieces of information that the children and young people shared in their interviews and not appreciated their importance. I could have followed up on some comments more than others, and unwittingly have given the child/young person an impression that

some topics were more meaningful. While exploring the data, I could have been more open to the results that fitted with my expectations such as more discrepancy in the cognitive domain. I actively sought and used supervision and mentoring opportunities to explore the reasoning in my methodological choices. The supervision team reviewed the emerging results. I was active in giving presentations at all stages of my research to encourage feedback and questioning from my colleagues.

4.6.2 Quantity of data – data management

A large amount of data was generated over this longitudinal study. The data were in different formats as a result of the mixed methods concurrent design. Data management becomes more challenging in this type of study and a flexible approach to storing and managing the data was required (Miles and Huberman, 1994). In addition to storing the scoring forms and all paperwork in a traditional filing cabinet, a Microsoft Excel workbook was used to store the data in a non-traditional manner. A separate worksheet was allocated to each case and the data were added to the workbooks in different areas of the page using a different colour of text. A mixture of text and numerical data were added e.g. field notes, SDQ scores, Harter scores, KIC scripts. Storing the quantitative and some of the qualitative data together helped with data management and also reinforced the fully integrated mixed methods design. All the data had equal priority irrespective of whether they were qualitative or quantitative in nature.

4.6.3 Within case analysis

The first stage of data analysis involved the analysis of results from individual cases. The cases were presented in the same written format with an opening description

of the case and then an outline of the results in the same order. The presentation format was determined to provide uniformity. The measures provided information from different functional categories. In line with the domains of concern in the brain injury literature (Appleton and Baldwin, 2009, Ponsford, 2013, Walker and Wicks, 2005), the following domains were selected and the results were divided accordingly

- Physical
- Cognitive
- Emotional/psychological
- Social
- Behavioural
- Communication
- School/Learning

All of the data was allocated to a domain, as outlined in Table 4.6 below. Within each domain the results were collated, integrated and presented as a description of discrepancy.

Table 4-6 Data collected from each case

Domain	Data collected from child/young person	Data available from others to compare
Physical	Mean scores in Harter Scales Raw scores in KIC Qualitative thematic data and percentage of scoreable chunks allocated to physical/active domain in SUI Skills identified in Cooking task and Executive Function Map	**Parent** report from KIC **Teacher** report from Harter Scales **Normative data** from Harter Scales and SUI **Researcher** report from Cooking Task
Cognitive	Item data from SDQ and KIC Skills identified in Cooking task and Executive Function Map	**Parent** report from SDQ and KIC **Normative data** from SDQ **Researcher** report from Cooking Task
Emotional/psychological	Item data from SDQ and KIC Percentage of scoreable chunks allocated to psychological domain in SUI	**Parent** report from SDQ and KIC **Normative data** from SDQ and SUI
Social	Item data from Harter Scales and SDQ Percentage of scoreable chunks allocated to social domain in SUI	**Teacher** report from Harter Scales **Parent** report from SDQ **Normative data** from Harter Scales, SDQ and SUI
Behavioural	Item data from Harter Scales, SDQ and KIC	**Teacher** report from Harter Scales **Parent** report from SDQ and KIC **Normative data** from Harter Scales and SDQ
Communication	Item data from KIC	**Parent** report from KIC
School/learning	Item data from Harter Scales and KIC	**Teacher** report from Harter Scales **Parent** report from KIC **Normative data** from Harter Scales

Measure of discrepancy

Discrepancy scores are frequently calculated in the adult literature of self-awareness following a brain injury (Long et al., 2014, Kelley et al., 2014, Bivona et al., 2014). Discrepancy scores represent the difference between the self-rating and that of others. In this study two discrepancy scores were generated. First the **self-others** discrepancy was determined in the same manner as other brain injury studies.

Three sets of data were compared for discrepancy between:

- Self vs parent
- Self vs teacher
- Self vs researcher

A self-other discrepancy was determined for each of the seven functional domains. Both the qualitative and quantitative data were analysed to give a measure of discrepancy.

A second description of discrepancy was afforded in this study of children and young people. The data in the cases could also be compared to the data for typically developing children i.e. the **self-norm discrepancy**. These data were unique to this study compared to other brain injury studies. A self-norm discrepancy was calculated for each case. The quantitative and qualitative data were combined and used to determine the level of discrepancy from the normative data that was available.

Qualitative analysis

As mentioned previously, the Self-Understanding Interview (SUI) data was given a numeric value, according to the "chunks" of data that were allocated a score (see Section 4.5.2 above). This quantitative data was compared to the data from typically developing children. There was a trend in the normative data that changed across childhood, whereby more of the chunks were assigned to the physical and active domains in the younger child, and then with increased age there were more chunks assigned to the social and finally the psychological domain (Damon and Hart, 1988). The data from each of the cases were compared to this developmental trend, and discrepancy was decided qualitatively.

In addition to this, the interview texts were acknowledged as a rich source of data. Qualitative analysis of these data provided depth and richness, to compliment the quantitative analysis. This additional analysis fulfilled the philosophy of the mixed methods research. The interview data from the SUI were analysed using thematic analysis. The five stages of thematic analysis were followed (Braun and Clarke, 2006)

1. Familiarise self with data
2. Generate initial codes
3. Search for themes
4. Review themes
5. Define and name themes

The audio data were transcribed personally and the transcribed data were imported into NVivo 10[10] software for analysis. Themes were established inductively i.e. themes emerged from the data with no prior theoretical framework being imposed (Braun and Clarke, 2006, Robson, 1993, Miles and Huberman, 1994). A full description of the thematic analysis and results are given in Chapter 7.

Capturing individual characteristics and profiles of participants is a central tenet in this case study research. So, following the establishment of an overall thematic structure, the individual differences in the participants' interviews were also examined. Each of the coded interviews was reviewed, and their most common themes were identified. Further qualitative analysis on each individual interview was beyond the scope of this study design. However, a frequency count was feasible, and was used to help describe the "flavour" of the conversations, and highlight similarities and differences between participants.

In a final review of the transcript data, the interviews were compared to some normative characteristics. The quality of the interviews were compared to the narrative pen portraits available (Harter, 2012a) and note was also made of the brevity of some of the responses and the level of prompting that had been required from the researcher. Although the Harter pen portraits are not exact pieces of narrative extracts, they are a representation of what could be expected at different ages and have been generated from large interview data sets (Harter, 2012a). They provide a benchmark to judge the interview data from the case studies against.

[10] NVivo software provided by QSR International http://www.qsrinternational.com/

The audio data from the KIC were also transcribed. The first part of the interview asked the child/young person about their accident and measured their knowledge of events surrounding and following the accident. It also included their knowledge of general and specific information regarding the brain. A qualitative note was added to the case summaries of how knowledgeable the children/young people were in each case. Note was made of changes to this narrative during the later visits and this was added to the descriptions of the children/young people when the change over time data were evaluated. Additionally, the narrative from the parents and the children/young people were compared for discrepancy values across the functional domains.

Field notes were taken at each of the visits and these were used to provide some context to the cases and were included to supplement the change over time data. The field notes included information such as who was present during the visits, who had organised the appointments, how engaged the child/young person was, which circumstances had changed since the previous visits etc.

Quantitative analysis

The exploratory nature of this study and the case study methodology indicated less emphasis on quantitative analysis. Many of the measures generated a numerical score, however, these were mostly ordinal data and parametric statistical analysis was not indicated. Descriptive statistics were used to examine the data in each of the cases. Numerical test scores were compared to developmental norms, where available (Harter Scales and SDQ). Terminology such as below norm, above norm,

was used rather than levels of significance so that the results from different tests could be combined to provide a descriptive summary for each of the functional domains.

Some exploratory correlations of the cross-case analysis were carried out using Microsoft Excel[11] software and NVivo software. In order to explore the developmental and recovery perspectives, the numerical data was explored in relation to age at injury and time since injury,

Merging the data

The mixed methodology of this study involved merging of the data. Some data were in the form of numerical scores and others were taken from written reports and interview data. Some of the qualitative data were "quantitized", that is transformed into numerical data. The interview data from the Self Understanding Interview were quantitized in two ways. The transcribed interview data were assigned chunks and the chunks were scored following the procedure in the manual. The data were scored from 1-4 (see section 4.5.2).

Additionally the transcribed and coded interview data were analysed to establish how many times a certain theme was coded to individual participants. N-Vivo software was able to produce reports of the quantitized frequencies of each participant. Some of the KIC data were also quantitized. The KIC interview data was collected in the form of a narrative that was transcribed verbatim from the participants and copied from the written forms of the parents. The KIC asked the

[11] Microsoft Excel software available from Microsoft Corporation http://office.microsoft.com/en-gb/excel/

participants and parents to report difficulties following their brain injury from a list and some of the answers were quite lengthy. They were converted to a yes/no response to make comparison easier. The narrative detail was included elsewhere. Additionally a knowledge score was determined from the answers to the first part of the interview and a Discrepancy Awareness Index was also derived from the parent and child KIC interview transcripts (Beardmore et al., 1999). This discrepancy score was calculated from the number of difficulties acknowledged by the parent but not endorsed by the participant. A higher score was indicative of lower self-awareness.

Visual data displays

A summary visual data display was created for each case (see Figure 4-2 for template). Visual data displays are recommended as preparation for cross case analysis, as the data for each case will be displayed in the same format (Miles and Huberman, 1994). For these results the discrepancy in each domain was displayed first as a self-others discrepancy and second as a self-norm discrepancy. A colour coded system was used to highlight the discrepancies and aid the overview of the cases. The first colour column contained the self-others discrepancy and the second colour column contained the self-norm discrepancy for each domain. Red indicated discrepancy between the self-reported data and others' report or normative data. Orange indicated that there was **some** agreement. For example there could have been agreement on one measure and not on another within the same domain. Green indicated that the self-report was aligned to the others report or to the normative data.

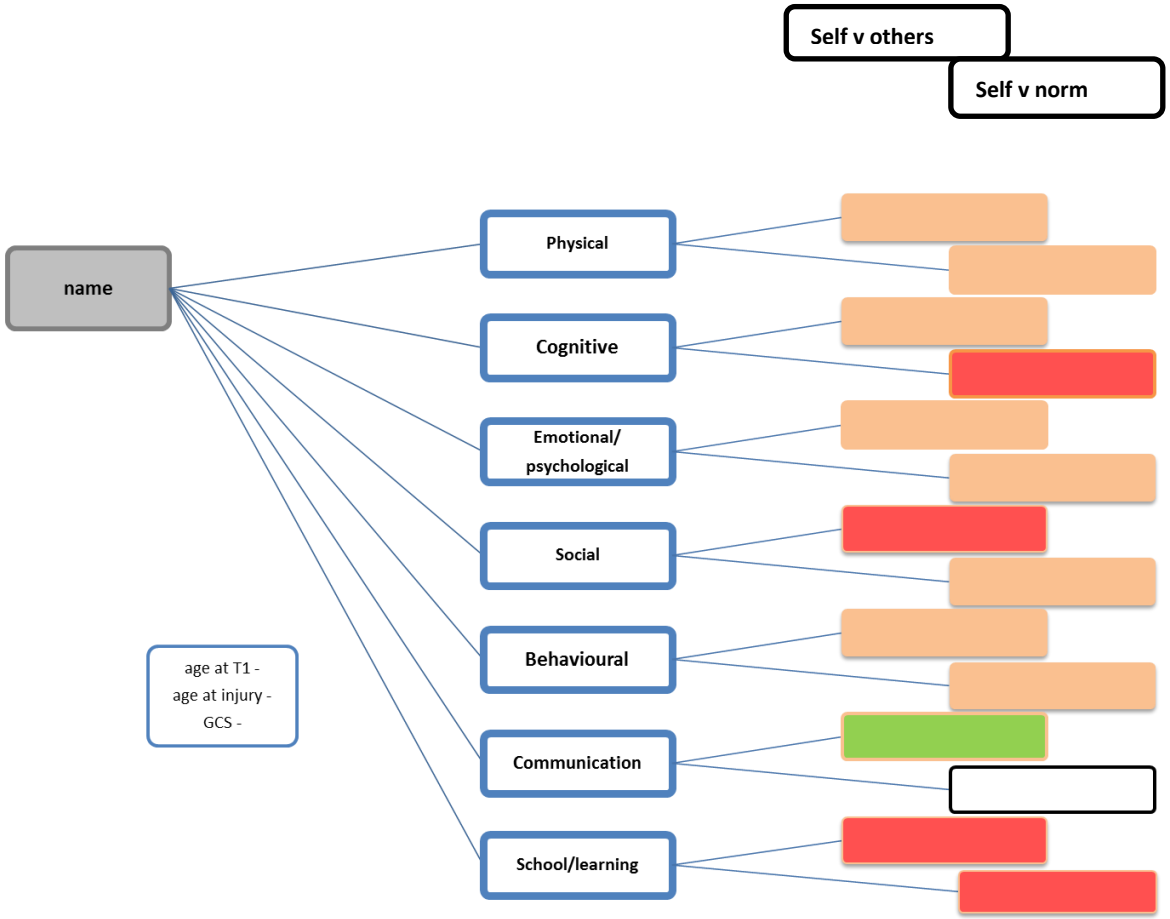

Figure 4-2: Template for visual data display

Change over time

Repeated data was collected from the majority of the measures, with the exception of the Executive Function Map that was only administered once. The change in scores and themes were examined visually and some correlations were carried out using Microsoft Excel software.

4.6.4 Across case analysis

Across case analysis was carried out following the within case analysis. The visual data displays were used to inspect patterns in the presentations. The data from the cases were ordered by age, age at injury, GCS scores etc. and examined visually to investigate if there was a developmental or injury severity pattern to the cases.

Each of the measures was explored across cases for patterns in the results. The data was examined visually to see if low scores on one test equated to low scores on another for particular cases. Exploration of the thematic analysis was also carried out across cases and reports were generated using the exploratory functions of NVivo 10, such as the age of the children/young people who spoke of their brain injury most.

Analysis of additional case variables

In this exploratory research study, there was no a-priori assumption that there would be any relationships between the data and the additional variables such as injury variables. However, some inspection of the pre-injury, injury and post-injury variables was carried out across the cases and reported in the cross-case analysis. A correlation was examined between age at injury, time since injury and GCS score

with the test results of Harter Scales (mean scores), SDQ (total scores), Cooking Task (total scores) and SUI (percentage of chunks allocated to physical, active, social and psychological domains).

4.7 Anticipated limitations and ethical considerations of the study

The methodology and protocol of this study was assessed and reviewed by two processes. First the Warwick Medical School upgrade process[12] and second by the ethics process[13]. Both of these review processes highlighted potential limitations and ethical considerations in the proposed study. The following steps were taken to reduce the impact of these issues on the study.

4.7.1 Limitations of the study

There were anticipated limitations to this research study. First was the sample size and second was the lack of external validity. There was a concern that the small sample size would reduce the power of the findings. Multiple case study research as outlined above can accommodate small numbers and findings can be substantiated if they are repeatedly found across cases. Heterogeneity of the sample is an issue in all brain injury research. The inclusion criteria helped to reduce this limitation. It has already been stated that clinical research can accommodate some heterogeneity as the study population reflect a typical clinical brain injury population.

[12] PhD candidates initially register for an MPhil then go through a formal upgrading process after one year (18 months for part-time students) to be registered for PhD.
[13] National Research Ethics Service http://www.nres.nhs.uk/

4.7.2 Ethical considerations

Key ethical issues

Risk of harm – children and young people are vulnerable. Children and young people who have suffered a brain injury are even more vulnerable. Talking about their brain injury and the events surrounding it may be upsetting in addition to the existing risk of being upset or feeling uncomfortable in a 1:1 situation talking about themselves.

Control measures – my own lengthy clinical experience was multidisciplinary in nature. I was used to working as part of a team and learning additional communication and psychological skills. I had sufficient knowledge of this client group to manage the risk. I was cautious not to be confrontational at any time. In addition the children were in fact used to talking about their brain injury. They knew they had been in rehabilitation centre or had received outreach therapy as a result of their brain injury. They were sufficiently exposed to talking about a brain injury for the risk of upset to be significantly reduced

Insignificant scientific value – the first ethical committee questioned the scientific value of the study and evaluated the possible risk to the children to be high.

Control measures – I reflected that the committee had not been convinced in part due to my lack of competence as a novice researcher. I lacked the skills to clearly articulate the research process and management of risk to a panel who do not share my knowledge of the clinical setting. The committee asked for a peer

review of the study and this was favourable. The committee were reassured of the scientific value of the study.

Participation bias – all the children and young people had accessed the services of The Children's Trust. There was a risk that only those who had had a positive experience would want to participate.

Control measures - I did not screen any of the families on this basis and approached all the families who met the criteria. It remained a possible risk.

Coercion – some of the families remain extremely loyal to The Children's Trust after their child/young person has left. There was a possibility that they perceived that they were giving something back by joining the study. I had been the treating therapist in a few of the cases and they may have felt that they were helping me if they participated.

Control measures – the initial letter of introduction came from the Chief Executive, and was a professional business letter to reduce the risk of coercion. I refrained from reminiscing with the participants during visits and I ceased calling those who did not return calls after a second attempt. It remained a low risk.

Loss to follow up – longitudinal research always carries the risk of loss to follow up, known as attrition. With small numbers to start with, there was a risk that the research would lose all value if too many participants were lost

Control measures – I included extra measures to keep in touch with the families throughout the study and expressed gratitude at every opportunity. I was very flexible with the appointments to ensure

that there was no extra burden on the families. I travelled to them in the majority of cases. The risk was reduced and seven participants remained in the study. I used case study methodology which has more tolerance of low numbers. This methodology significantly reduced this ethical issue.

The new application (11/LO/1833) received a favourable ethical opinion by the NRES Committee London - Fulham on 29 November 2011 (see Appendix 12) subject to two minor changes. My reply to the committee confirmed:

"I have removed the picture form the supporting illustrations as requested
I have altered the invitation letter to indicate to the parents that I will visit and collect consent in person."

4.8 Chapter summary

This chapter has outlined the theoretical focus for the study. A means of capturing data from different sources has been established, that can be used to evaluate the discrepancy between the child report and that of others. Additionally, data is available from typical development that can be used to measure a discrepancy from the norm. A method of evaluating the cases has been described. Also a method of understanding the themes and then conducting some cross-case analysis has been outlined. I have anticipated all of the ethical issues and have a plan to minimise them.

The next chapter will introduce the participants who consented to take part in this research.

5 Chapter 5: Overview of Cases

5.1 Introduction

This chapter introduces the reader to the fifteen cases recruited to this study.

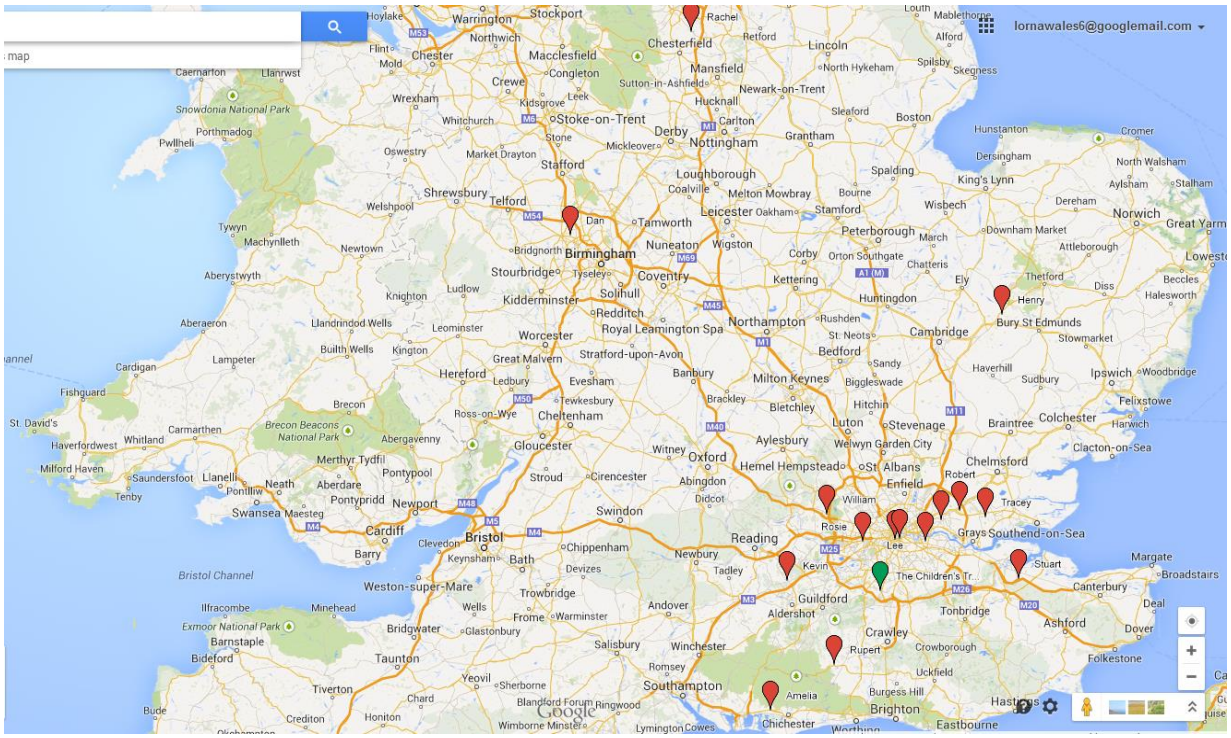

Figure 5-1: Geographical distribution of cases

The participants were recruited from The Children's Trust. The Children's Trust has a national catchment area, although it has a greater profile in the South of England. Most of the children and young people in this study were from London and the Home Counties. A few cases lived further away i.e. Derbyshire, Suffolk and Birmingham (see Figure 5-1).

Although the children represented a range of ages, the majority were over 12 years at injury (see Table 5-1). The inclusion criteria screened out those who were less than 1 year post-injury and those who were over 5 years post-injury. The children

and young people who were recruited represented a range of times post-injury (see Table 5-1).

Table 5-1: Demographic detail of cases *=IMD scores

	Age at injury (years)	*Time since injury (years)*	*Glasgow Coma Score*	*Socioeconomic Status (SES)**	*Number of visits*
William	5.9	3.5	6	6.77	2
Rosie	8.6	4.8	3	11.02	1
Dan	9.5	1.2	8	7.94	4
Henry	10.1	3.8	severe	10.65	3
Peter	11.8	3.3	not known	42.20	1
Kevin	12.9	4.6	9	3.66	2
Robert	13.2	4.6	10	12.26	4
Stuart	13.8	4.0	6	11.81	4
Rachel	14.5	1.7	6	20.43	4
Tracey	14.9	3.7	7	5.49	4
Rupert	16.4	2.0	8	7.94	3
Amelia	16.4	2.7	6	7.29	4
Dale	16.8	1.7	9	35.59	1
Debbie	17.0	1.6	3	38.81	4
Lee	17.1	1.7	6	34.28	4
Male n=10 Female n=5	**Mean=13.26 (3.45)**	**Mean=3**	**Mean=7**	**17.08**	

The participants were recruited from the two main brain injury services at The Children's Trust, residential rehabilitation and Brain Injury Community Team. The former service offered a period of intensive residential rehabilitation and the latter offered an intensive 1 week assessment with follow up service in the community. Ten young people were recruited from the residential service and five from the

community service. The children and young people who could not be located or declined to join the study had a similar SES profile to those recruited.

All of the children and young people have been given a pseudonym to protect their anonymity. The cases are introduced in this chapter, ordered by how long they remained in the study and therefore how much data was collected (see Table 5-2).

Table 5-2: Overview of order of cases presented

Name	Age at injury	Amount of data collected	Reason for drop-out
Rosie	8 years 7 months	T1	No reason given
Dale	16 years 10 months	T1	"fed up talking about brain injury"
Peter	11 years 9 months	T1	No reply to calls
William	5 years 11 months	T1 and T2	Moved away
Kevin	12 years 11 months	T1 and T2	No reply to calls
Rupert	16 years 5 months	T1, T2 and T3	No reply to calls
Henry	10 years 1 month	T1, T2 and T3	No reply to calls
Amelia	16 years 5 months	T1, T2, T3 and T4	
Lee	17 years 1 month	T1, T2, T3 and T4	
Robert	13 years 2 months	T1, T2, T3 and T4	
Tracey	14 years 11 months	T1, T2, T3 and T4	
Debbie	17 years	T1, T2, T3 and T4	
Stuart	13 years 10 months	T1, T2, T3 and T4	
Rachel	14 years 6 months	T1, T2, T3 and T4	

Dan	9 years 6 months	T1, T2, T3 and T4

5.2 Case summary –Rosie

Rosie is a thirteen-year-old girl who sustained a severe brain injury (GCS 7)[14] as a result of a Road Traffic Accident –pedestrian vs car when she was aged 8 years 7 months. There is a legal case. Her SES score is 11.02 (low deprivation). Her radiological report indicated:

- Diffuse oedematous changes
- Left subdural haematoma
- Bilateral subarachnoid haematoma
- Number of skull fractures

Rosie had two neurosurgical procedures

- Insertion of ICP bolt and
- Craniotomy

Rosie had no residential neurorehabilitation and returned to her previous school. She had a specialist assessment and recommendations including liaison with local services in 2008 (1 year post-injury).

At recruitment, Rosie was attending a local high school and had no contact with therapy services but was known to Special Needs Coordinator (SENCO) at school. Rosie and her mother were fully engaged at the T1 visit and provided detailed information. However, Rosie's mother called the next day to withdraw from the

[14] Glasgow Coma Scale scoring system = Severe GCS 3-8; Moderate, GCS 9–12; Mild, GCS 13-15

study citing the legal case as a reason. Data from the teacher could therefore not be collected.

Rosie does not recall the events of her accident. She is able to retell the key facts that others have told her. She has some memory of being in hospital. She has a global view of how the brain works i.e. it controls your whole body but little knowledge of what can happen to the brain when it is injured.

Rosie's interview was free flowing. There was little need for probing and follow up questions. She appeared relaxed throughout the interview. She had her mother present but did not seem to be affected by her presence. She was open and expressive throughout.

5.3 Case summary – Dale

Dale is an eighteen-year-old young man who sustained a complicated moderate brain injury (GCS 9) as a result of a Road Traffic Accident –pedestrian vs bus when he was aged 16 years 10 months. There is no legal case. His SES score is 35.59 (high deprivation). His radiological reports indicated:

- Subarachnoid blood in sulci of R parietal lobe
- Diffuse axonal damage
- Complicated skull fractures

Dale had no residential neurorehabilitation and returned to his previous school. He had a specialist assessment and recommendations including liaison with local services in Spring 2011 (6 months post-injury). During this period, Dale and his

mother raised concerns about emotional/ psychological adjustment. A referral was made to Child and Adolescent Mental Health Services.

At T1 Dale was awaiting assessment by a specialist neuropsychological team. He was engaged and cooperative throughout the data collection visit.

At T2 Dale indicated that he no longer wished to participate in the study. He stated that he was "fed up" talking about his brain injury and wanted to "move on"

Dale had memory of the events leading up to his accident and then he had memories of waking up in the hospital (KIC). He had knowledge of how the brain works and what can happen to the brain if it is injured.

Dale was engaged in the interview throughout, despite interruption from his mother. He gave full and elaborate answers to the questions and little probing was required.

5.4 Case summary – Peter

Peter is a 15year old young man who sustained a severe brain injury (GCS not known) as a result of a Road Traffic Accident – bike versus car when he was aged 11 years 9 months. There is no legal case. His SES score is 42.2 (high deprivation). His radiological report indicated

- Diffuse axonal injury
- Left frontal lobe injury

He had raised intracranial pressure but no surgical intervention was required.

Peter had no residential neurorehabilitation and returned to his previous school. He had a specialist assessment and recommendations including liaison with local services in 2009 (4 months post-injury).

At recruitment, Peter was still attending the local school and had some tutorial support.

Peter was withdrawn from the study at T2. His mother was not home at the appointment time and had forgotten to alert Peter to be home. Another time was to be arranged but this did not prove successful. A few attempts were made via text message to Mum but a follow up visit could not be confirmed.

Peter has no recollection of his accident and cannot recall the information that he has been told by others about the event. He only knows that he was riding his bike and got hit by a car. He has some limited and general knowledge about the brain, how it functions and how it can be affected if it is injured in an accident.

The interview narrative included brief answers to the questions and a lot of probing questions were required to encourage Peter to elaborate on the dialogue.

5.5 Case summary – William

William is a nine-year-old boy who sustained a severe brain injury (GCS 6) as a result of a Road Traffic Accident –pedestrian vs car when he was aged five years 11 months. His deprivation score was 6.77 (low deprivation). There was a legal case. His radiological report indicated

- Diffuse axonal injury

- Right scalp swelling associated with a small sub-dural collection over the right side of the tentorium and
- Petechial haemorrhages in the right frontal and temporal lobes.

William received three months of residential neurorehabilitation and returned to his previous school with support.

On discharge from residential rehabilitation, William was able to walk short distances with close supervision but was still dependent on his wheelchair for longer distances. He had reduced safety awareness and was impulsive. He required consistent support and monitoring to manage his behaviour and had ongoing cognitive and language difficulties that required 1:1 support in the classroom.

At recruitment, William was still attending the local primary school and was still receiving weekly physiotherapy. He had access to OT and SLT weekly at school and had ongoing support in the classroom.

William had no recollection of his accident and could not recall the information that he had been told by others about the event. He had limited recall of the time in hospital. He had very little knowledge about the brain, how it functions, and how it can be affected if it is injured in an accident

5.6 Case summary - Kevin

Kevin is a seventeen-year-old young man who sustained a complicated moderate brain injury (GCS 9) as a result of a Road Traffic Accident –pedestrian vs bus when he was aged 12 years 11 months. There is no legal case. His SES score is 3.66 (low deprivation). His radiological report indicated:

- Intracranial bleeding
- Small subdural collection over tentorium and posterior interhemispheric fissure
- Thin collection over the R fronto-temporal area
- Slight midline shift to L
- Small SAH over interpeduncular cistern
- Contusion right parieto-occipital area
- Contra-coup injury
- Multiple fractures of basal skull
- Fracture right humerus, clavical and zygoma

Kevin had no residential neurorehabilitation and returned to his previous school. He had a specialist assessment and recommendations and liaison with local services in his home area.

Specialist report indicated difficulties in impulsivity, generation of ideas, high level language, high level executive, intention tremor when fatigue, and poor safety awareness.

At recruitment, Kevin was attending a local college and had no contact with therapy services but was known to the Special Needs Coordinator at school.

Kevin had no recollection of his accident but could recall in detail the information that he had been told by others about the event. He had limited recall of the time in hospital. He had some knowledge about the brain and how it functions from school lessons but had less accurate knowledge of how the brain can be affected if it is injured in an accident. He described two extremes that included having a headache or a fatal head injury.

It was easy to engage Kevin in the interview and he gave full answers with little prompting.

5.7 Case summary - Rupert

Rupert is an eighteen-year-old young man who sustained a severe brain injury (GCS 3) as a result of a Road Traffic Accident – restrained rear seat passenger when he was aged 16 years 5 months. His SES score is 7.94 (low deprivation). There is a legal case. His radiological report only indicated

- Diffuse axonal injury

He had a number of medical complications while in the acute hospital setting and spent a prolonged period of time in the Intensive Care Unit. He had neurosurgical and medical procedures including tracheostomy.

Rupert received 10 months of residential neurorehabilitation and moved to further inpatient rehabilitation for young adults before moving home with his mother and her partner.

On discharge from residential rehabilitation Rupert had significant difficulties in all functional domains. He was reliant on an indoor powered wheelchair, his communication was difficult and he had severe fatigue issues that led to his timetable for the day being significantly reduced.

At recruitment, Rupert was in the rehabilitation setting for young adults and had a full programme of therapy. Rupert had no recollection of his accident and could recall only a few pieces of information that he had been told by others about the event. He had limited recall of the time in hospital. He had good knowledge of the brain, how it functions and how it can be affected if it is injured in an accident.

Rupert had left school and was at college at the time of his accident. He continued to access education in the rehabilitation setting. Rupert's fatigue was an ongoing concern at T1. The interview was brief and there was little elaboration in his answers.

5.8 Case summary - Henry

Henry is a thirteen-year-old boy who sustained a severe brain injury (GCS not known) as a result of a Road Traffic Accident –cyclist vs car when he was aged 10 years 1 month. His SES score is 10.65 (low deprivation). There is a legal case. His radiological report indicated:

- Diffuse brain injury
- Depressed frcture temporal bone
- CSF otorrhoea
- Scattered petecial haemorrhages bilaterally around the splenum of the corpus callosum, thalami (right>left), right inferior parietal lobe and possibly left temporal lobe
- Small extradural haematomas right temporal and right frontal regions

Henry had neurosurgical and medical procedures including insertion of extra ventricular drain and evacuation of retro-orbital haematoma.

Henry did not receive in-patient rehabilitation following his accident. He returned to school. One year later he had a programme of support from an outreach Brain Injury Community Team for 1 year that involved support and education in the home and the school setting, to manage strategies and respond to ongoing difficulties. The team highlighted difficulties with language, high level cognitive and motor difficulties.

At recruitment, Henry was still attending the local high school. He had no recollection of his accident but could give an account of the events leading up to it. He stated that he had not been told much information by others about the accident. He had a few key facts about the brain, how it functions and how it can be affected if it is injured in an accident.

Henry engaged in the interview throughout but his responses were rather brief and the probing was necessary to maintain the flow of the interview.

5.9 Case summary - Amelia

Amelia is a nineteen-year-old young lady who sustained a severe brain injury (GCS 6) as a result of a Road Traffic Accident – unrestrained front seat passenger when she was aged 16 years 5 months. Her SES score is 7.29 (low deprivation). There is a legal case. Her radiological report only indicated

- Diffuse axonal injury with small areas of haemorrhage

She had neurosurgical and medical procedures including intracranial pressure monitoring for 48 hours, ventilation and tracheostomy.

Amelia received four months of residential neurorehabilitation and returned to her previous school with support.

On discharge from residential rehabilitation Amelia was independently mobile. She had high level motor, cognitive, communication and social difficulties. She had full time 1:1 support on return to school outside of the classroom. She had a programme of support from an outreach Brain Injury Community Team for 1 year

that involved support and education in the home and the school setting to manage strategies and respond to ongoing difficulties.

At recruitment, Amelia was attending the local sixth form college and was working part time at a local supermarket. She had support from psychology services, but no other therapy involvement. Amelia had no recollection of her accident and could only recall the information that she had been told by others about the event. She had some recall of the time in hospital. She had some knowledge about the brain, how it functions and how it can be affected if it is injured in an accident.

Amelia engaged in the interviews with clear and elaborate responses at times. She became upset during the T1 interview as she talked about her accident and how difficult she had found it to come to terms with.

5.10 Case summary - Lee

Lee is an eighteen-year-old young man who sustained a severe brain injury (GCS 6) as a result of a Road Traffic Accident –motorscooter vs car when he was aged 17 years 1 month. There is a legal case. Deprivation score 34.28 (high deprivation). His radiological report indicated

- Fracture left clavicle
- Fracture left rib
- Left pneumothorax

He had neurosurgical and medical procedures including stem of bleed from subclavian vein, craniectomy, surgical removal of right temporo-parietal clot, tracheostomy, blood transfusion, lumbar puncture.and gastrostomy.

Lee received eight months of residential neurorehabilitation and moved to further inpatient rehabilitation for young adults before moving home with his mother and stepfather. On discharge from the primary residential rehabilitation setting Lee was able to walk short distances with close supervision but was still dependent on his wheelchair for longer distances. He had significant ongoing physical, communication and social difficulties.

At recruitment, Lee was in the rehabilitation setting for young adults and had a full programme of therapy. Lee was able to give a detailed account of his accident and time in hospital. He had a good knowledge of the brain, how it functions and how it can be affected if it is injured in an accident.

Lee had difficulty expressing himself at T1 and the narrative was rather brief with short responses and some stereotypical phrases e.g. you can't be serious the whole of your life. Many of his responses lacked elaboration and were not open to interviewer encouragement e.g. "Just having fun init" and "I'd be boring init".

5.11 Case summary - Robert

Robert is a seventeen-year-old young man who sustained a moderate brain injury (GCS 10) as a result of a Road Traffic Accident –pedestrian vs car when he was aged 13 years 2months. His SES score is 12.26 (low deprivation). There is no legal case. His radiological report indicated

- Diffuse axonal injury
- Multiple petechial haemorrhages at the grey/white matter junction of both cerebral hemispheres
- Left cerebellar haemorrhage

- Some low density change in the brainstem
- Fracture left tibia/fibula
- Fracture left ulna

Robert had neurosurgical and medical procedures including being intubated and ventilated, ICP bolt inserted and gastrostomy.

Robert received 14 months of residential neurorehabilitation and returned to his previous school with support. On discharge from residential rehabilitation Robert had significant physical, cognitive and communication difficulties that required 1:1 support in the classroom. He was dependent on an attendant-propelled or electric wheelchair and used a communication aid to support his speech intelligibility.

At recruitment, Robert was still attending the local high school. Robert had no recollection of his accident and could not recall the information that he had been told by others about the event either. He had no recall of the time in hospital. He had little knowledge about the brain, how it functions and how it can be affected if it is injured in an accident.

The interview was very brief and the narrative was very unresponsive with little elaboration. When the researcher used the probe questions, these were usually met with a "don't know" response.

5.12 Case summary - Tracey

Tracey is a nineteen-year-old young lady who sustained a severe brain injury (GCS 3) as a result of a boating accident when she was aged 14 years 11 months. There is a legal case. Her SES score is 5.49 (low deprivation). Her radiological report indicated

- Depressed R temporal fracture
- Right temporal intracerebral haematoma
- Petrous bone fracture

She had neurosurgical and medical procedures including occlusion of R middle cerebral artery, ventilated 6 days, craniotomy, evacuation of haematoma and insertion of extraventricular drain, extubated, titanium cranioplasty, fresh intracerebral haemorrhage - treated with therapeutic lumbar puncture.

Tracey received seven months of residential neurorehabilitation and returned to her previous school with support. On discharge from residential rehabilitation Tracey was independently mobile. She had ongoing physical, and high level communication and cognitive difficulties, that were affecting her social abilities.

At recruitment, Tracey was living at home and still attending the local high school. She was still receiving some additional learning and examination accommodations. Tracey had no recollection of her accident but gave a detailed account of the events leading up to it. She could recall the information that she had been told by others about the event. She had limited recall of the time in hospital. She had knowledge about the brain, how it functions and how it can be affected if it is injured in an accident.

Tracey's narrative was extensive and elaborate. She responded to questions fully and was able to articulate reasons for what she was saying. The interview flowed naturally.

5.13 Case summary - Debbie

Debbie is an eighteen-year-old young lady who sustained a severe brain injury (GCS 3) as a result of a Road Traffic Accident –pedestrian vs car when she was aged 17 years. Her deprivation score was 38.81 (high deprivation). There is no legal case. Her radiological report indicated

- Fracture petrous temporal bone
- Subarrachnoiod haematoma in frontal lobe
- Subdural haematoma (SDH)
- Fracture pelvis
- Fracture right humerus
- Fracture right clavicle

Debbie had neurosurgical and medical procedures including left decompressive craniectomy and evacuation of acute SDH, insertion of ICP bolt, and treatment of a right lung contusion

Debbie received four months of residential neurorehabilitation. On discharge from residential rehabilitation, she did not have an educational placement identified and was liaising with Connexions regarding the next step e.g. college or vocational course. She was independently mobile and had some high level physical impairment, but ongoing cognitive and social communication difficulties.

At recruitment, Debbie was attending the local college with support. Debbie had no recollection of her accident and could not recollect the information that she had been told by others about the event. She had no recall of the time in hospital. She had little knowledge about the brain, how it functions and how it can be affected if

it is injured in an accident. She said that she had been offered this information but had chosen not to have it.

Debbie's interview involved many brief answers. I needed to use the prompts to facilitate elaboration of her answers. The narrative did not flow.

5.14 Case summary - Stuart

Stuart is a seventeen-year-old young man who sustained a severe brain injury (GCS 6) as a result of an assault when he was aged 13 years 10 months. There is a legal case. His deprivation score is 11.81 (low deprivation). His radiological report indicated

- Subarachnoid haemorrhage
- Small lesion in cerebellar vermis;
- Generalised cerebral oedema;

Stuart had neurosurgical and medical procedures including being intubated and ventilated.

Stuart received three months of residential neurorehabilitation and returned to his previous high school with support. On discharge from residential rehabilitation Stuart was independently mobile. He had significant high level cognitive and communication difficulties. He had a programme of support from an outreach Brain Injury Community Team for one year that involved support and education in the home and the school setting to manage strategies and respond to ongoing difficulties.

At recruitment, Stuart was still attending the local high school and was still requiring accommodations in learning and exams. Stuart had no recollection of his incident but gave a detailed account of the events leading up to it. He had limited recall of the time in hospital. He had good knowledge of the brain, how it functions and how it can be affected if it is injured in an accident.

The interview narrative was extensive and elaborative. Few prompts were required and the interview flowed easily.

5.15 Case summary - Rachel

Rachel is a sixteen-year-old young lady who sustained a severe brain injury (GCS 6) as a result of a Road Traffic Accident –restrained front seat passenger when she was aged 14 years 6 months. There is a legal case. Her deprivation score is 20.43 (low deprivation). Her radiological report indicated

- Contre-coup injury
- Diffuse axonal injury
- Subarachnoid haemorrhage
- Unstable fracture cervical vertebra
- Cervical disc disruption
- Vertebral spinous process fracture at l5
- Posterior teardrop fracture of superior vertebral margin at c3
- Right pelvic fractures
- Fracture left acetabulum
- Fracture 9th rib on left side and partial collapse of left lung
- Dislocation right elbow
- Right ulnar and distal radius fractures

Rachel had neurosurgical, medical and orthopaedic procedures including neuroprotective measures, IVP bolt insertion, tracheostomy, HALO inserted and secured, K-wiring right wrist, plaster cast right arm, Anterior cervical discectomy fusion and plating during a 5 month stay in hospital.

Rachel received four months of residential neurorehabilitation after a 1 month period at home. She initially returned home and attended a specialist school for young people with acquired brain injury for a short time. She then attended the local high school on a restricted timetable with 1:1 support.

On discharge from residential rehabilitation, Rachel was able to walk short distances with a rollator but was still dependent on her wheelchair for longer distances. Her safety awareness was compromised as she was extremely impulsive. She required constant support and monitoring to manage her agitation and disorientation. She had ongoing severe cognitive and language difficulties that required 1:1 support in the home and classroom environments.

5.16 Case summary - Dan

Dan is a ten-year-old boy who sustained a severe brain injury (GCS 8) as a result of a Road Traffic Accident –cyclist vs car when he was aged nine years 6 months. His deprivation score was 7.94 (low deprivation). There is not a legal case. His radiological report indicated

- Fracture right parietal bone,
- Fracture floor anterior cranial fossa,
- Fracture wall of r eye socket,
- Fracture sphenoid bone.

- Bleeding contusions of r temporal and frontal lobes,
- Subdural and extradural haematomas of r frontal lobe,
- Damage to corpus callosum, basal ganglia, midbrain.
- Bilateral femur fractures, r tibia fracture –

Dan had neurosurgical, medical and orthopaedic procedures including internal fixation of his left leg fractures and Botox injections.

Dan received six months of residential neurorehabilitation and returned to his previous school with support.

On discharge from residential rehabilitation Dan was independently mobile indoors. He required supervision and used his wheelchair for long distances. He was impulsive and easily distracted. Fatigue affected his activity and participation in functional tasks including outdoor mobility. Strategies were put in place to manage behavioural outbursts and his ongoing cognitive, speech and language, and communication needs.

At recruitment, Dan was still attending the local primary school and was still receiving weekly physiotherapy. He had access to OT and SLT weekly at school and had ongoing support in the classroom.

The interview was very brief and the answers were very short and lacked much detail.

Dan had no recollection of his accident or the time spent in hospital. He could not recall the information that he had been told by others about the events. He had

minimal knowledge about the brain, how it functions and how it can be affected if it is injured in an accident.

5.17 Summary

This chapter has provided an overview of the participants that were recruited to this study. They sustained their brain injuries in a range of ways at various ages. They have all had different injury and post injury experiences. In the first of the results chapters, the next chapter will present the result for the individual cases from the first data collection visit.

6 Chapter 6: Results – individual discrepancy data

6.1 Introduction

This chapter reports the results from the fifteen individual cases. In particular, as stated in Chapter 4, the discrepancy data is reported in order to address the first two research questions:

1. **What is the level of self-awareness in school age children who have suffered a moderate to severe traumatic brain injury?**
2. **How does the level of self-awareness following a TBI in childhood compare to typically developing children?**

The data collected for comparison was mainly collected on the first visit (T1), but continued until the third visit (T3). The data collection continued because some parents and teachers did not respond until the second visit and the Cooking Task took place at the third visit. All of these data were assigned to the domains of physical, cognitive, emotional/psychological, social, communication, behavioural and school/learning for comparison. There are data from self-report in addition to parent, teacher and researcher reports (see Table 4.6 for the comparative data for each domain).

The data are reported as a measure of discrepancy in order to establish a level of self-awareness. The levels of self-awareness will be reported in visual representations at the end of this chapter.

Discrepancy is examined in this chapter when the self-report data are compared to other sources (**self-others discrepancy**) and to normative values (**self-norm discrepancy**)

There is considered to be a **self-others discrepancy**, when the child rates themselves higher than the other person, regardless of magnitude, or when the parent/teacher identifies a problem that is not endorsed by the child/young person. This method is not without problems, but is in keeping with the methods used in the adult literature. The reports from others are not an objective measure of the child/young person's ability, but rather a judgement of whether the adult feels they have difficulties in each domain. Parents and teachers may be inclined to overstate the ability of the children and young people whom they know to have experienced a traumatic event. They may also report more easily the deficits that are more dramatic and pay less attention to the more subtle deficits. Despite these confounding factors, the data in this chapter will give an indication of the level of self-awareness using this commonly adopted technique from the adult literature.

Additionally, the self-report data are examined with reference to the normative values and the discrepancy from the norm is reported here for each case in turn (**self-norm discrepancy**). There is considered to be a discrepancy when the child's self-report is above that expected at the normative value, regardless of magnitude i.e. they may be over-rating their ability.

A deviation from the norm represents a judgement of how the child/young person sees their ability in each of the social, school, physical domains, compared to others

of their age. Difficulties in many of the functional domains would be expected as the children and young people in this study have a moderate/severe TBI. If they were aware of their new acquired deficits, it may be expected that their judgement would be below that typical of their age.

There are however, many factors that will affect the way that the children and young people report their level of ability. Across the different domains of function, the child/young will in fact have a varied level of ability e.g. greater social skills than physical skills or scholastic skills. However, for the reporting in this chapter, it is acknowledged that one of the factors that affect the way that children/young people report their abilities following a brain injury is their level of self-awareness. Comparison with others and normative data is used to give an indication of levels of self-awareness through the use of discrepancy scores.

When the SDQ results are used as comparison to the norm (cognitive, emotional/psychological, social and behavioural domains), the terms from the assessment are used e.g. “close to average”. At other times the data are compared to normative values such as the Harter Scales. In these cases, the difference is noted simply as above or below the norm.

Reporting the presence of self-other and self-norm discrepancies in this manner will only give an impression of how the young person judges their abilities in each of the domains. The researcher will be able to develop an overall profile of the level of self-awareness of each participant. A visual representation of the discrepancies is give at the end of the chapter in visual data displays.

The younger children (Dan and William) do not have SDQ self-report data to compare and none of the cases have normative data from the communication domain to compare. Only the self-others discrepancy will be reported for the communication domain.

The Cooking Task was administered at T3 and by that time some of the children/young people had left the study. The Cooking Task results will not be included in the first five cases.

Towards the end of the chapter the cases are summarised in a visual form. These visual data displays show the level of self-other and self-norm discrepancy for each domain. Each case is presented on one page to facilitate the cross-case comparison that will continue in the next chapter.

6.2 Discrepancy results-Rosie (8years 7 months at injury; 13 years at recruitment)

There was no teacher data to compare for Rosie. The self-report data from Harter scales were only compared to normative values (see Figure 6-1).

6.2.1 Physical domain

Self-others discrepancy: Although both self-report and parent report acknowledged difficulties with the physical tasks of 'walking' and 'getting tired easily', parent report also identified problems 'writing' that was not endorsed in self-report (see Table 6-2).

Self-norm discrepancy: Self-report was below the normative value in the items "athletic competence" and "physical appearance" (see Figure 6-1). There were less

scoreable chunks in the interview data as would be expected at this age (see Figure 6-2).

6.2.2 Cognitive domain

Self-others discrepancy: Self and parent report both identified "hyperactivity and attentional difficulties" and rated this item **high**. "Concentration" and "remembering things" were also identified by self and parent report as a difficulty in the KIC (see Table 6-1). However, parent also reported difficulty "planning and organising" but this was not endorsed in the self-report (see Table 6-2)

Self-norm discrepancy: self-report of "hyperactivity and attentional difficulties" was **high** compared to norm (see Table 6-1).

6.2.3 Emotional/psychological domain

Self-others discrepancy: Self and parent report agreed difficulties with "feeling and behaviour" (see Table 6-2). Self and parent report identified difficulty with "emotional distress" and "overall stress" but parent report rated the difficulties more severely (see Table 6-1).

Self-norm discrepancy: Self report of "emotional distress" and "overall stress" were high and slightly raised (see Table 6-1). The profile of scoreable chunks had less assigned to the psychological domain (see Figure 6-2). At her age, more chunks assigned to social and psychological than physical and active domains would be expected. (See Damon and Hart, 1988).

6.2.4 Social domain

Self-others discrepancy: Self-report and parent report in the SDQ item 'difficulties getting along with other children' differed by degree. Self-rating was **close to average** and parent report was **very high** (See Table 6-1).

Self-norm discrepancy: Self-report was higher than the normative value in 'social acceptance' and 'close friendship' at the maximum value of 4.0. Self-report was below the norm for "romantic appeal" (see Figure 6-1). Self-report of "getting along with other children" was **close to average** (see Table 6-1). The greatest percentage of scoreable chunks in the interview data were assigned to the social domain (33%), followed by the active domain (17%). Only 11% of the chunks are scored in the physical and psychological domain. This pattern of less physical chunks and more social chunks is the shift that is expected with increasing age (see Figure 6-2).

6.2.5 Behavioural domain

Self-others discrepancy: There was agreement between self and parent report that "feelings and behaviour" were an area of difficulty (see Table 6-2). Parent report identified "behaviour difficulties" and poor "kind and helpful behaviour". These were not endorsed in self-report (see Table 6-1).

Self-norm discrepancy: Self-report was higher than the normative value at the maximum of 4.0 for the item "behavioural conduct" (see Figure 6-1). Self-report of "behavioural difficulties" and "kind and helpful behaviour" were **close to average** (see Table 6-1).

6.2.6 Communication domain

Self-others discrepancy: Self and parent report agreed that there were difficulties in communication (see Table 6-2).

6.2.7 School/learning domain

Self-others discrepancy: Parent report identified 'keeping up with the rest of the class' and 'writing' as difficult but these were not endorsed by self-report. Self-report identified difficulty "reading" and this was not endorsed in parent report (see Table 6-2).

Self-norm discrepancy: Self report of "scholastic competence" and "job competence" were below norm (see Figure 6-1)

6.2.8 Rosie summary

Rosie presented with some discrepancy across all but one domain (communication). There was most discrepancy in the School/learning domain. She was able to recognise some of her difficulties but was not reporting at an age equivalent level.

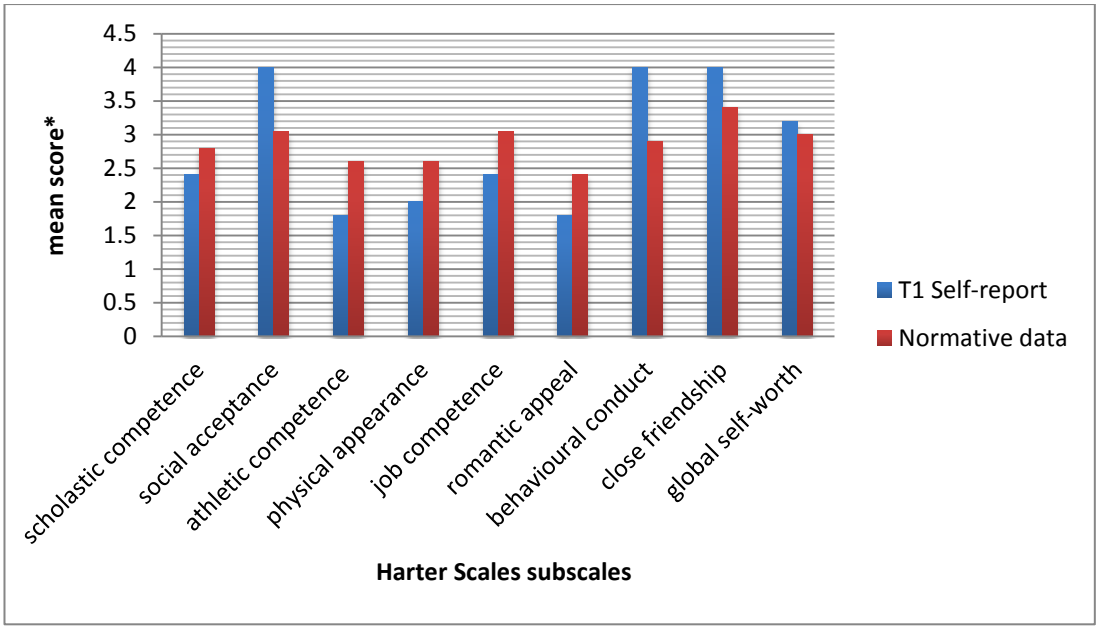

Figure 6-1: Rosie - Harter Scales self-rating scores compared to normative data. *mean score range 1-4

Table 6-1: Rosie - SDQ self-ratings and parent ratings. *Descriptors – very low, low, close to average, slightly raised, high, very high

	Self-report raw scores	Descriptor*	Parent report raw scores	Descriptor	Discrepancy
SDQ overall stress	15	Slightly raised	25	Very high	Yes
Emotional distress	6	High	7	Very high	Yes
Behavioural difficulties	2	Close to average	5	High	Yes
Hyperactivity and attentional difficulties	7	High	8	High	No
Difficulties getting along with other children	0	Close to average	5	Very high	Yes
Kind and helpful behaviour	9	Close to average	6	Low	Yes

Table 6-2: Rosie - KIC self- ratings and parent ratings

Problems identified	Self-report	Parent report	Discrepancy
Concentrating	Yes	Yes	No
Getting tired easily	Yeah I get really tired	Yes	No
Remembering things	Yes	Yes	No
Keeping up with the rest of the class	No	Yes	Yes
Planning things, getting organised	No	Yes	Yes
Walking problems	Yes	Yes	No
Writing problems	No	Yes	Yes
Speaking or talking	Yes	Yes	No
Saying sentences so they make sense	Sometimes yeah	Sometimes	No
Understanding what other people say	Yes	Not interested in what other people have to say	No
Reading	Yes	Not very fond of reading	No
Feelings and behaviour	Yes	Yes	No
KIC Discrepancy Index (higher score=poorer awareness)			**3**

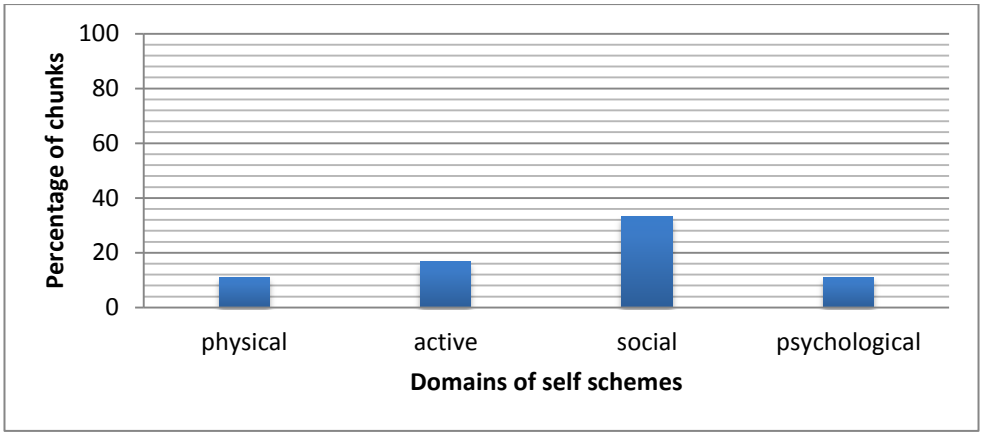

Figure 6-2: Rosie - percentage of SUI chunks coded to each domain at T1

6.3 Discrepancy results- Dale (16 years 10 months at injury; 18 years at recruitment)

There is no teacher report data for Dale. The self-report data from Harter scales were only compared to normative values (see Figure 6-3).

6.3.1 Physical domain

Self-others discrepancy: Self and parent-report agree in the physical items of KIC i.e. "getting tired easily", "walking problems" and "writing problems" (see Table 6-4).

Self-norm discrepancy: Self-report was higher than the normative value in "athletic competence" and "physical appearance" (see Figure 6-3). The scoreable chunks in the interview data had more allocated to the physical domain than would be expected at his age (Figure 6-4).

6.3.2 Cognitive domain

Self-others discrepancy: There was agreement between the self and parent report that Dale had difficulty "concentrating" and "remembering things". An additional item "planning things/ getting organised" was identified by parent report but not

endorsed by self-report (see Table 6-4). Parent report was higher than self-report for “hyperactivity and attentional difficulties” (see Table 6-3).

Self-norm discrepancy: Self-report was **close to average** for “hyperactivity and attentional difficulties” (see Table 6-3).

6.3.3 Emotional/psychological domain

Self-others discrepancy: Parent report was higher than self-report for “emotional distress”, and “overall stress” (see Table 6-3). Self and parent report both identified ‘feelings and behaviour’ as an area of difficulty (see Table 6-4)

Self-norm discrepancy: Self-report of “emotional distress” and “overall stress” was **close to average** (see Table 6-3). There were scoreable chunks from the interview data that were allocated to the psychological domain as would be expected at this age (see Figure 6-4).

6.3.4 Social domain

Self-others discrepancy: Self-rating and parent rating acknowledged some difficulty “getting along with other children” (see Table 6-3)

Self-norm discrepancy: Self-rating was greater than the normative data in the “social competence”, “close friendship” and “romantic appeal” items (see Figure 6-3). Self-rating of “getting along with other children” was **slightly raised** compared to the norm (see Table 6-3). Some of the scoreable chunks of interview data were allocated to the social domain as would be expected at this age (see Figure 6-4).

6.3.5 Behavioural domain

Self-others discrepancy: Both self-report and parent report agreed that “feelings and behaviour” was an area of difficulty (see Table 6-4). Self-report of “behaviour

difficulties" and "kind and helpful behaviour" was lower than parent report (see Table 6-3).

Self-norm discrepancy: Self-report of "behavioural conduct" and "behavioural difficulties" were higher than the norm, but the difference was very small (See Figure 3-3 and Table 3-3). Self-report of "behaviour difficulties" and "kind and helpful behaviour" were **close to average** (see Table 6-3).

6.3.6 Communication domain

Self-others discrepancy: Self and parent report agree that there were no difficulties "saying sentences so they make sense" and "understanding what other people say". However, parent report identified difficulty with "speaking/talking" that was not endorsed by self-report (see Table 6-4).

6.3.7 School/job domain

Self-others discrepancy: Self and parent reports agreed a difficulty "keeping up with the rest of class". Additionally, they agreed that there were no difficulties "reading" or "writing" (see Table 6-4).

Self-norm discrepancy: Self-report was greater than the normative value in "scholastic competence" and lower than the norm for "job competence", although the difference was very small (see Figure 6-3).

6.3.8 Dale Summary

Dale had some self-awareness across all domains. There was agreement between the self-report and report of others in 3/7 domains. The self-report was at an age appropriate level in 3/6 domains.

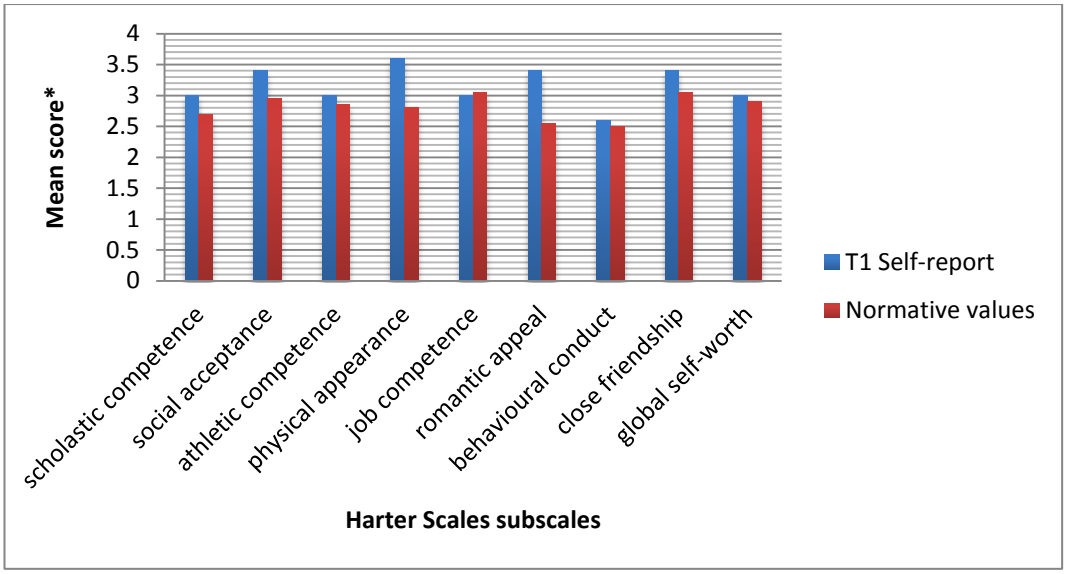

Figure 6-3: Dale - Harter Scales self-rating scores compared to normative data. *mean score range 1-4

Table 6-3: Dale - SDQ self-ratings and parent ratings *Descriptors – very low, low, close to average, high, very high

	Self-report raw scores	Descriptor*	Parent report raw scores	Descriptor	Discrepancy
SDQ overall stress	11	Close to average	17	High	Yes
Emotional distress	2	Close to average	4	Slightly raised	Yes
Behavioural difficulties	2	Close to average	4	High	Yes
Hyperactivity and attentional difficulties	4	Close to average	6	Slightly raised	Yes
Difficulties getting along with other children	3	Slightly raised	3	Slightly raised	No
Kind and helpful behaviour	8	Close to average	4	Very low	Yes

Table 6-4: Dale - KIC self-ratings and parent ratings

Problems identified	Self-report	Parent report	Discrepancy
Concentrating	Yes	Yes	No
Getting tired easily	Kind of, yeah kind of, get a bit lazy	Yes, lacks energy	No
Remembering things	Yeah sometimes	Yes	No
Keeping up with the rest of the class	Yes	Yes	No
Planning things, getting organised	No	Yes	Yes
Walking problems	No	No	No
Writing problems	No	No	No
Speaking or talking	No	Yes	Yes
Saying sentences so they make sense	No	No	No
Understanding what other people say	No	No	No
Reading	No	No	No
Feelings and behaviour	Yes	Yes	No
KIC Discrepancy Index (higher score=poorer awareness)			**2**

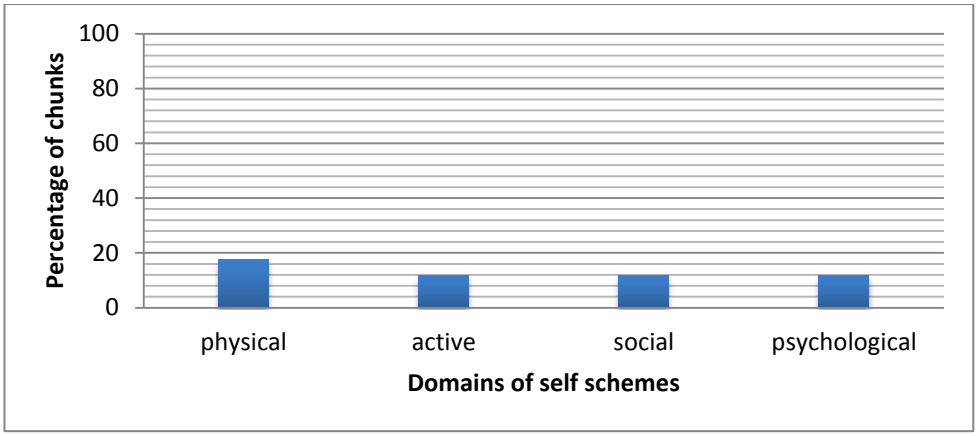

Figure 6-4: Dale - Percentage of SUI chunks coded to each domain at T1

6.4 Discrepancy results-Peter (11 years 9 months at injury; 15 years at recruitment)

6.4.1 Physical domain

Self-others discrepancy: Self-rating was higher than teacher rating for "physical appearance" and "athletic competence" (see Figure 6-5). While self and parent report agree that there were no "walking" or "writing" difficulties, parent report identified "getting tired easily" and this was not endorsed by self-report (see Table 6-6).

Self-norm discrepancy: Self-report was higher than the normative value for "physical appearance" and lower than the norm for "athletic competence" (see Figure 6-5). The greatest percentage of scoreable chunks of interview data was in the physical domain (33%). When compared to normative data, this pattern of distribution is like that of a younger child (see Damon and Hart). Less physical and active chunks and more in the psychological and social domain would be expected at this age (see Figure 6-6).

6.4.2 Cognitive domain

Self-others discrepancy: Self and parent report agreed difficulties "concentrating". However parent report also identified difficulties with "memory" and "planning things/getting organised" which were not endorsed in the self-report (see Table 6). Neither self nor parent report identified "hyperactivity and attentional difficulties" (see Table 6-5).

Self-norm discrepancy: Self-report of "hyperactivity and attentional difficulties" was **close to average** (see Table 6-5).

6.4.3 Emotional/psychological domain

Self-others discrepancy: Peter and his mother rated 'feelings and behaviour' as an area of difficulty in the KIC (see Table 6-6). Parent report of "emotional distress" and "overall stress" were higher than self-report (see Table 6-5).

Self-norm discrepancy: Self-report of "emotional distress" was **close to average** and "overall stress" was **slightly raised** compared to norms (see Table 6-5). There were no scoreable chunks in the psychological domain that would be expected at this age (see Figure 6-6).

6.4.4 Social domain

Self-others discrepancy: Parent report was higher than self-report for the item "difficulty getting along with other children" (see Table 5). Self-report was greater than teacher report for "social competence" and "romantic appeal". It was less than teacher report for "close friendship" and the differences were very small (see Figure 6-5).

Self-norm discrepancy: Self-rating of "social competence" and "romantic appeal" were above the normative value for his age and below the norm for "close friendship" (see Figure 6-5). Self-rating of "getting along with other children" was **slightly raised** compared to the norm (see Table 6-5). There were scoreable chunks allocated to the social domain, as expected at this age (see Figure 6-6).

6.4.5 Behavioural domain

Self-others discrepancy: Peter overrated his ability compared to the teacher in the item "behavioural conduct" where the teacher rating was at the minimum score of 1.0 (see Figure 6-5). Parent report rated and "kind and helpful behaviour" lower

than self-report (see Table 6-5). Self and parent report agreed problems with "feelings and behaviour" and "behavioural difficulties" (see Tables 6-5 and 6-6).

Self-norm discrepancy: Self-report of "behavioural conduct" was close to norm and "behavioural difficulties" and "kind and helpful behaviour" were below the norm (see Figure 6-5 and Table 6-5).

6.4.6 Communication domain

Self-others discrepancy: Parent report identified difficulties "saying things so that they make sense" and "understanding what other people say" that were not endorsed by Peter. Self and parent report agreed no difficulty "speaking or talking" (see Table 6-6).

6.4.7 School/job domain

Self-others discrepancy: Self-report of "scholastic competence" was greater than teacher report and "job competence" slightly lower than the teacher report (see Figure 6-5). Both self and parent report identified "difficulties keeping up with the rest of the class" and both agreed no difficulty "reading" and "writing" (see Table 6-6).

Self-norm discrepancy: Self-report of "scholastic competence" and "job competence" was lower than the normative values (see Figure 6-5).

6.4.8 Peter summary

There was only one area of agreement in Peter's profile. He was able to report cognitive difficulties at a similar level to his peers. However, in all other areas, Peter often rated himself higher than others and higher than expected of his age.

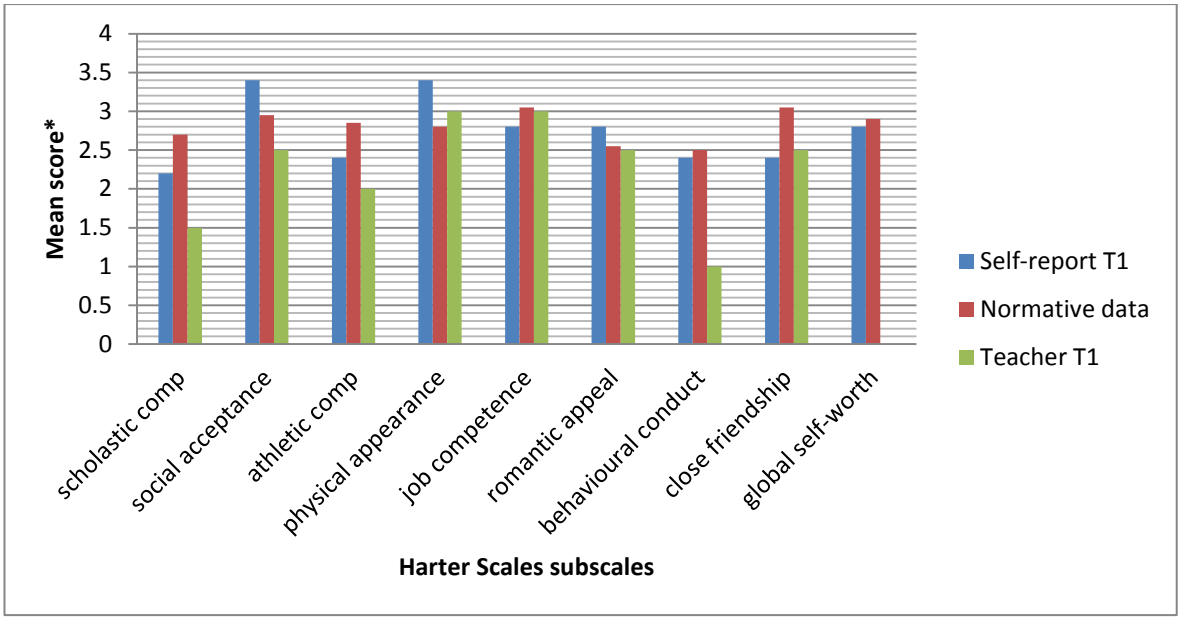

Figure 6-5: Peter - Harter Scales self-rating scores compared to teacher scores and normative values. *Mean score range 1-4

Table 6-5: SDQ self-ratings and parent ratings. *Descriptors – very low, low, close to average, high, very high

	Self-report raw score	Descriptor*	Parent report	Descriptor	Discrepancy
SDQ overall stress	16	slightly raised	22	very high	Yes
Emotional distress	3	close to average	5	high	Yes
Behavioural difficulties	6	very high	7	very high	No
Hyperactivity and attentional difficulties	4	close to average	5	close to average	No
Difficulties getting along with other children	3	slightly raised	5	very high	Yes
Kind and helpful behaviour	5	low	8	close to average	No

Table 6-6: Peter - KIC self-ratings and parent ratings

Problems identified	Self-report	Parent report	Discrepancy
Concentrating	Yes	Yes	No
Getting tired easily	No, no	Yes	Yes
Remembering things	Not any more	Yes	Yes
Keeping up with the rest of the class	Yes	Yes	No
Planning things, getting organized	No	Yes	Yes
Walking problems	No	No	No
Writing problems	No	No	No
Speaking or talking	No	No	No
Saying sentences so they make sense	No	Yes	Yes
Understanding what other people say	No	Yes	Yes
Reading	No	No	No
Feelings and behaviour	Yes	Yes	No
KIC Discrepancy Index (higher score=poorer awareness)			**5**

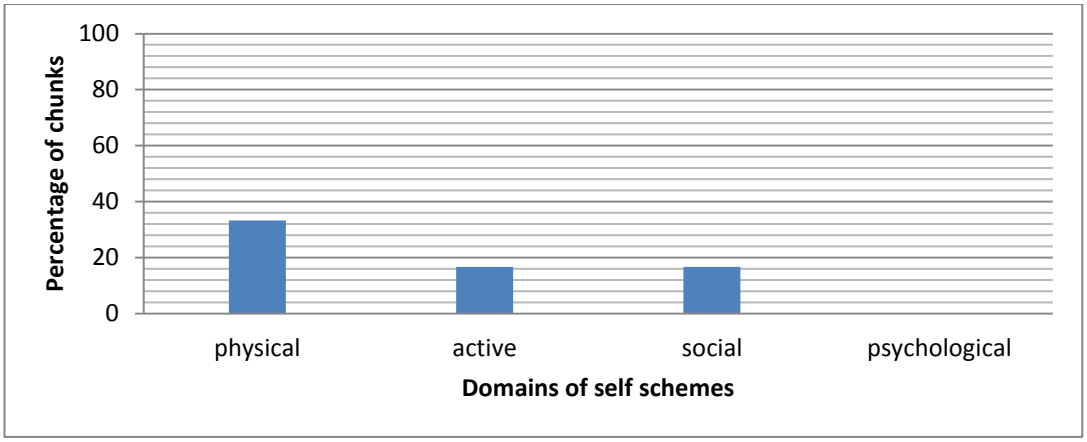

Figure 6-6: Peter - Percentage of SUI chunks coded to each domain at T1

6.5 Discrepancy results –William (5 years 11 months at injury; 9 years at recruitment)

William's teacher data was provided at T2 and the Harter Scales data is therefore compared to William's T2 data.

6.5.1 Physical domain

Self-others discrepancy: Self-report was greater than teacher report in "athletic competence". There was missing teacher comparative data for "physical appearance" (see Figure 6-7).

Self-norm discrepancy: Self-report was below norm value in "athletic competence" and "physical appearance" (see Figure 6-7). The scoreable chunks from interview data related mostly to the physical and active domains (28%) compared to the social and psychological domains (6%). This pattern of scored chunks is expected at this age (see Figure 6-8).

6.5.2 Cognitive domain

Self-others discrepancy: Self and parent report identified difficulties "concentrating" and "remembering things" (see Table 6- 8). Parent report also

noted difficulties with the higher level cognitive skills of “planning and organising”. William did not concur.

Self-norm discrepancy: no comparative data available

6.5.3 Emotional/psychological domain

Self-others discrepancy: Parent report identified difficulties in feelings and behaviours that were not endorsed by self-report (see Table 6-8).

Self-norm discrepancy: There were some emerging scoreable chunks in the psychological domain as expected at this age (see Figure 6-8).

6.5.4 Social domain

Self-others discrepancy: Self-report was below teacher report for “social acceptance” (see Figure 6-7).

Self-norm discrepancy: Self-report was below the norm for “social acceptance” (see Figure 6-7). There were some emerging scoreable chunks in the social domain as expected at this age (see Figure 6-8).

6.5.5 Behavioural domain

Self-others discrepancy: Self-report was below teacher report in “behavioural conduct” (see Figure 6-7). Parent report identified difficulty with “feelings and behaviour” that was not endorsed in self-report (see Table 6-8).

Self-norm discrepancy: Self-report was above norm in the item ‘behavioural conduct’ (see Figure 6-8).

6.5.6 Communication domain

Self-others discrepancy: parent report identified areas of communication difficulty in the KIC and added that the concerns were more apparent when he was tired. William did not recognise these difficulties (see Table 6-8).

6.5.7 School/learning domain

Self-others discrepancy: Self-report of "scholastic competence" was lower than teacher ratings. The self-rating was at the minimum score of 1.0 (see Figure 6-7). Self and parent report identified difficulties "keeping up with the rest of the class, but only parent report included difficulties with "reading" and "writing" (see Table 6-8).

Self-norm discrepancy: Self-report of "scholastic competence" was below norm (see Figure 6-7).

6.5.8 William summary

There was less data to compare in William's case as he was too young to complete the SDQ. There was discrepancy/missing data across all domains. There was only one area of agreement in William's profile. He was able to report emotional/psychological difficulties at a similar level to his peers and there was some self-reporting at an age equivalent level in the interview data.

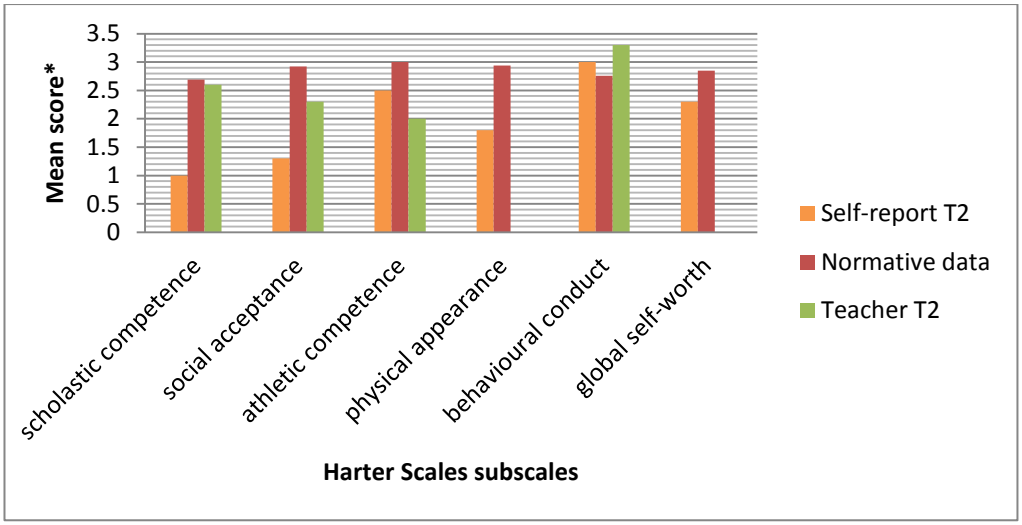

Figure 6-7: William - Harter Scales self-rating scores compared to teacher ratings and normative values *mean scores range 1-4

Table 6-7: William - SDQ parent ratings *Descriptors – very low, low, close to average, high, very high

	Parent report raw scores	Self-report raw scores	Descriptor*
SDQ overall stress	27	Data not available	Very high
Emotional distress	8		Very high
Behavioural difficulties	4		High
Hyperactivity and attentional difficulties	10		Very high
Difficulties getting along with other children	5		Very high
Kind and helpful behaviour	7		Slightly low

Table 6-8: William - KIC self-ratings and parent ratings

Problems identified	Self-report	Parent report	Discrepancy
Concentrating	Yes	Yes	No
Getting tired **easily**	Yes	Yes	No
Remembering things	Yes	Yes	No
Keeping up with the rest of the class	Yes	Yes	No
Planning things, getting organised	No	Yes	Yes
Walking problems	No	Yes	Yes
Writing problems	No	Yes	Yes
Speaking or talking	No	Yes	Yes
Saying sentences so they make sense	No	Yes	Yes
Understanding what other people say	No	Yes	Yes
Reading	No	Yes	Yes
Feelings and behaviour	No	Yes	Yes
KIC Discrepancy Index (higher score=poorer awareness)			**8**

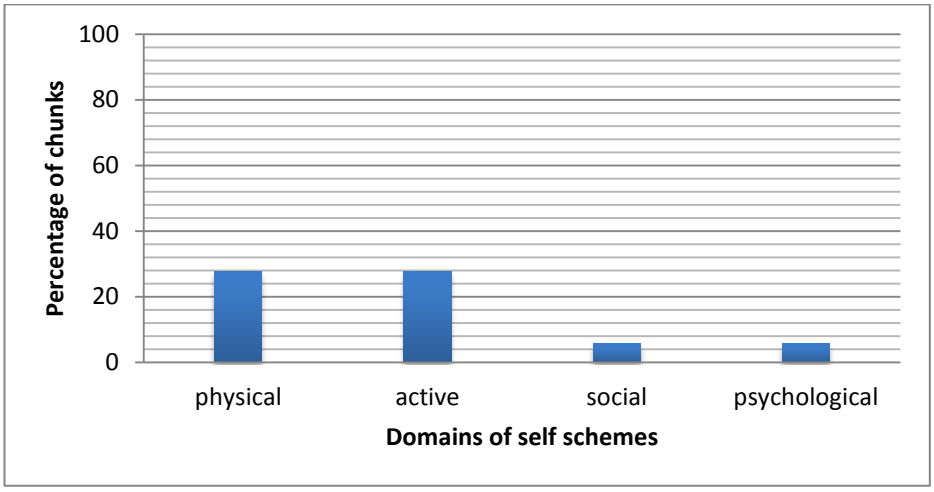

Figure 6-8: William - Percentage of SUI chunks coded to each domain at T1

6.6 Discrepancy results – Kevin (12 years 11 months at injury; 17 years at recruitment)

Kevin's teacher data was provided at T2 and the Harter Scales data is therefore compared to Kevin's T2 data.

6.6.1 Physical domain

Self-others discrepancy: Self-report was lower than teacher report in the items "athletic competence" and "physical appearance" (see Figure 6-9). Self and parent report agree that there were no difficulties "getting tired easily", "walking" or "writing" (see Table 6-10).

Self-norm discrepancy: Self-rating was below the norm value in the items "athletic competence" and "physical appearance" (see figure 6-9). The lowest percentage of scoreable chunks in the interview data were assigned to the physical domain. This is the profile expected at this age (see Damon and Hart, 1988)

6.6.2 Cognitive domain

Self-others discrepancy: Self-report identified that "memory" had always been an area of difficulty, even prior to his brain injury. His mother did not recognise this, but noted that he had difficulty "planning things and getting organised". Kevin did not concur (see Table 6-10). Self and parent report agree no "hyperactivity and attentional difficulties" and no difficulties "concentrating" (see Table 6-10).

Self-norm discrepancy: Self report of "hyperactivity and attentional difficulties" was **close to average** (see Table 6-9).

6.6.3 Emotional/psychological domain

Self-others discrepancy: Neither self or parent report identified any difficulty with "feelings and behaviour", "emotional distress" and "overall stress" (see Tables 6-9 and 6-10).

Self-norm discrepancy: Self-report was **close to average** for "emotional distress" and "overall stress" (see Table 6-9). There were scoreable chunks in the interview data that were assigned to the psychological domain as expected at his age (see Damon & Hart, 1988).

6.6.4 Social domain

Self-others discrepancy: Self-report was below teacher report for "social competence", "romantic appeal" and "close friendship" (see Figure 6-9). Parent report was higher than self-report for "difficulties getting on with other children" (see Table 6-9).

Self-norm discrepancy: Self-report for "social competence", "close friendship" and "difficulty getting on with other children" was **close to average.** "Romantic appeal" was above the norm (see Figure 6-9 and Table 6-9). The social domain was represented in the distribution of the scoreable chunks from the interview data. This profile is typical of this age (see Damon& Hart, 1988).

6.6.5 Behavioural domain

Self-others discrepancy: Self-report was below teacher report for "behavioural conduct" (see Figure 6-9). Neither self nor parent report identified "behavioural difficulties" or difficulty with "feelings and behaviour". However, parent report of "kind and helpful behaviour'" was lower than self-report (see Tables 6-9 and 6-10).

Self-norm discrepancy: Self-report rated above the normative value in "behavioural conduct" (see Figure 6-9). Self-report for "behaviour difficulties" and "kind and helpful behaviour" were **close to average** (see Table 6-9).

6.6.6 Communication domain

Self-others discrepancy: Kevin reports difficulty "saying sentences so they make sense" but this was not endorsed by his mother. Self and parent agreed that there were no difficulties "speaking or talking" or "understanding what other people say" (see Table 6-10).

6.6.7 School/job domain

Self-norm discrepancy: Self and teacher report agreement for the items "scholastic competence" and" job competence" both assigning the maximum score of 4.0 for "job competence" (see Figure 6-9).

Self-others discrepancy: Self-report was close to norm for "scholastic competence" and above norm for "job competence" (see Figure 6-9).

6.6.8 Kevin summary

Kevin had some self-awareness that was evident across all of the domains. The area of greatest discrepancy was the social domain and the area of greatest agreement was the emotional/psychological domain, where he agreed with the report of others and also reported at an age equivalent level. There was some self-report at an age-matched level, consistently in the cognitive and emotional/psychological domains.

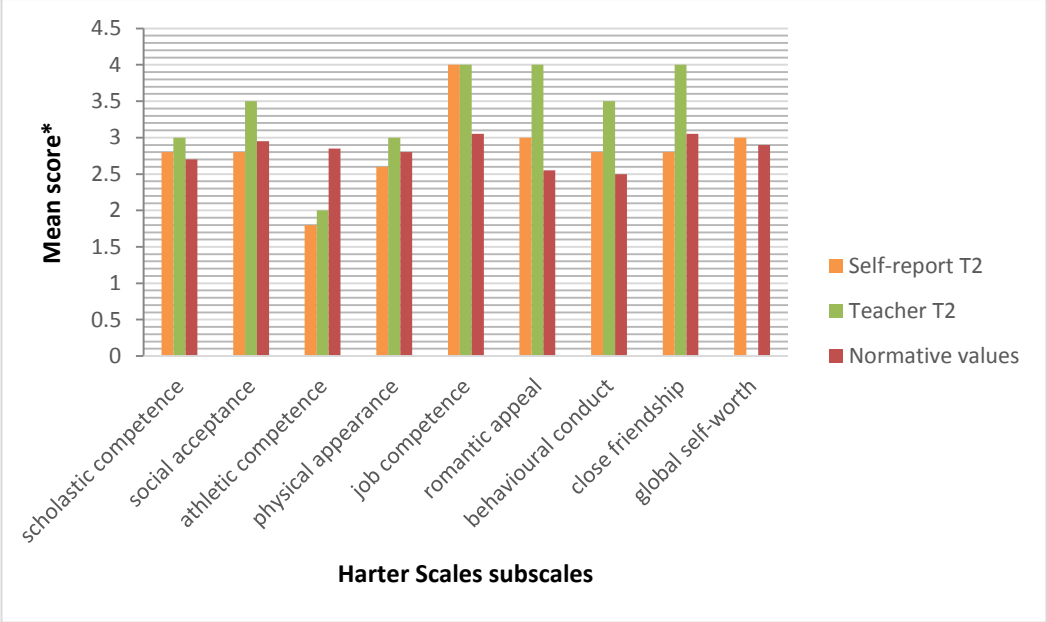

Figure 6-9: Kevin - Harter Scales self-report scores compared to teacher report and normative values at T2

Table 6-9: Kevin - SDQ self-ratings and parent ratings *Descriptors – very low, low, close to average, high, very high

	Self-report raw score	Descriptors*	Parent report raw scores	Descriptor	Discrepancy
SDQ overall stress	8	Close to average	10	Close to average	No
Emotional distress	0	Close to average	0	Close to average	No
Behavioural difficulties	2	Close to average	2	Close to average	No
Hyperactivity and attentional difficulties	4	Close to average	3	Close to average	No
Difficulties getting along with other children	2	Close to average	5	Very high	Yes
Kind and helpful behaviour	7	Close to average	5	Very low	Yes

Table 6-10: Kevin - KIC self and parent ratings

Problems identified	Self-report	Parent report	Discrepancy
Concentrating	No	No	No
Getting tired easily	No	No	No
Remembering things	No	No	No
Keeping up with the rest of the class	No	No	No
Planning things, getting organised	No	Yes	Yes
Walking problems	No	No	No
Writing problems	No	No	No
Speaking or talking	No	No	No
Saying sentences so they make sense	Yes	No	Yes
Understanding what other people say	No	No	No
Reading	No	No	No
Feelings and behaviour	No	No	No
KIC Discrepancy Index (higher score=poorer self-awareness			**2**

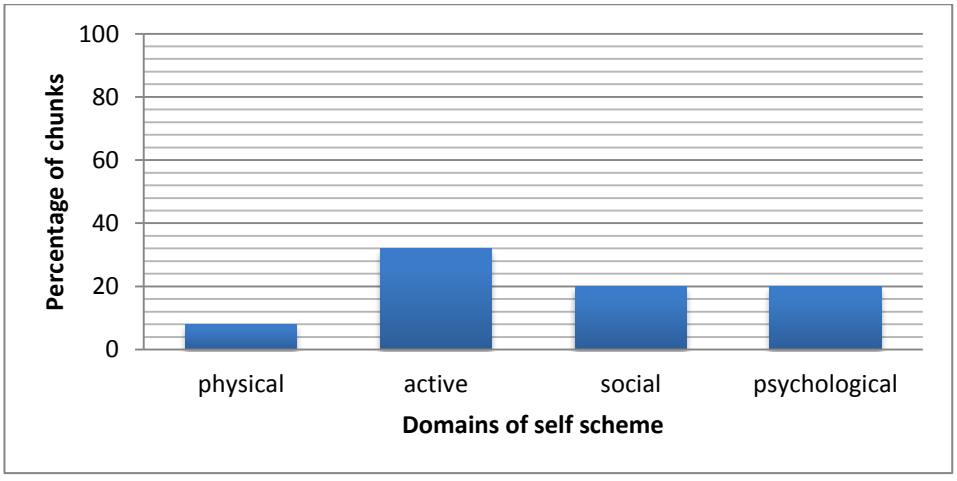

Figure 6-10: Kevin - Percentage of SUI chunks coded to each domain at T1

6.7 Discrepancy results –Rupert (16 years 5 months at injury; 19 years at recruitment)

6.7.1 Physical domain

Self-others discrepancy: Self-rating was higher than teacher report in "athletic competence" and similar to teacher report for "physical appearance" (see Figure 6-11). He did not recognise problems with writing in the KIC that the parent report identified but both self and parent report acknowledged walking problems and "getting tired easily" (see Table 6-12). There was no discrepancy in the Cooking Task (see Table 6-13). Rupert recognised that he would have physical problems with the task and this was endorsed by the therapist low score (see Table 6-13).

Self-norm discrepancy: Self-rating in the Harter Scale was lower than the norm in the items "physical appearance "and "athletic competence" but only by a small amount (see Figure 6-11). Much of the scoreable chunks in the interview data were assigned to the physical and active domain. This is not typical of his age (see Figure 6-12).

6.7.2 Cognitive domain

Self-others discrepancy: Self-report was lower than parent report in "hyperactivity and attentional difficulties" (see Table 6-11). There was agreement between self and parent report for "concentrating" and "remembering things" but no data from self-report for "planning and organising" (see Table 6-12). He recognised that he had cognitive difficulties with the Cooking Task when reflecting on his performance in line with the high error score in the task.

Self-norm discrepancy: The self-report for "hyperactivity and attentional difficulties" was **high** compared to norms (see Table 6-11). The total error score in the Cooking Task was more than that reported in the pilot normative sample (Chevingard et al 2010)

6.7.3 Emotional/psychological domain

Self-others discrepancy: Neither self-report nor parent report indicated "emotional distress" or "emotional stress" in the SDQ (see Table 6-11). Parent report indicated a difficulty in "feelings and behaviour" that was not endorsed in the self-rating (see Table 6-12)

Self-norm discrepancy: Self-report of "emotional distress" and "overall stress" was **close to average** (see Table 6-11). The profile of the interview chunks was similar to a younger child. There were fewer items in the psychological domain than expected at his age (see Damon & Hart 1988).

6.7.4 Social domain

Self-others discrepancy: Self-report was greater than teacher report for "romantic appeal". Self-rating of "close friendship" was at the ceiling of 4.0 and was greater than the teacher report. Conversely, teacher report reached the ceiling and was greater than the self-report in the item of "social acceptance" (see Figure 6-11). Self and parent report agreed that there was no difficulty "getting along with other children" (see Table 6-11).

Self-others discrepancy: Self-report was greater than norm in "social acceptance", "romantic appeal" and "close friendship" (see Figure 6-11). Self-report was **close to average** for "getting along with other children" and there was evidence of

scoreable chunks being allocated to the social domain in line with age (see Figure 6-12).

6.7.5 Behavioural domain

Self-others discrepancy: Self-rating of "behavioural conduct" and "kind and helpful behaviour" were below that of teacher and parent (see Figure 6-11 and Table 6-11). Self and parent report agreed no "behaviour difficulties" (see Table 6-11). However, difficulty with "feelings and behaviour" was rated as a problem by parent and not endorsed in the self-report (see Table 6-12).

Self-norm discrepancy: Self report was **close to average** for "behaviour difficulties" but **low** for "kind and helpful behaviour" (see Table 6-11). Self-report was also below the norm for "behavioural conduct" (see Figure 6-11).

6.7.6 Communication domain

Self-others discrepancy: Self and parent agreed difficulty in "speaking/talking" and "saying sentences so that they make sense". However, parent reported difficulty "understanding what other people say" that was not endorsed in self-report (see Table 6-12).

6.7.7 School/work

Self-others discrepancy: Self-report was higher than teacher report in the item "job competence". Teacher report was at the lowest score of 1.0 while in "scholastic competence" teacher rating was marginally higher than self-report (see Figure 6-11). There was no comparative data for "keeping up with the rest of the class" (see Table 6-12). Self and parent report agreed "reading" difficulties but disagreed for "writing" problems (see Table 6-12).

Self-norm discrepancy: Self report of "scholastic competence" was below the norm value but similar to norm for "job competence" (see Figure 6-11).

6.7.8 Rupert summary

Rupert had some self-awareness that was evident across all domains. He was able to recognise some areas of difficulty but was not reporting at an age-equivalent level, particularly in the cognitive domain. He was more able to recognise difficulties in the Cooking Task than the self-report measures.

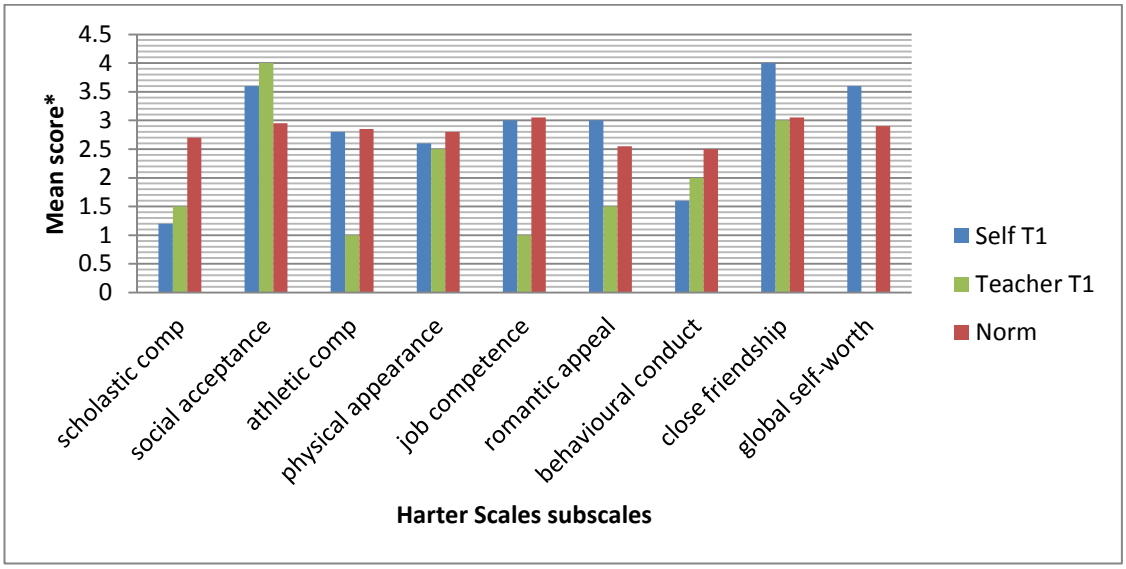

Figure 6-11: Rupert - Harter Scales self-report scores compared to teacher scores and normative values *mean score range 1-4

Table 6-11: Rupert - SDQ self-ratings and parent ratings *Descriptors – very low, low, close to average, high, very high

	Self-report raw scores	Descriptor*	Parent report raw scores	Descriptor	Discrepancy
SDQ overall stress	10	Close to average	10	Close to average	No
Emotional distress	1	Close to average	3	Close to average	No
Behavioural difficulties	1	Close to average	1	Close to average	No
Hyperactivity and attentional difficulties	7	High	6	Slightly raised	Yes
Difficulties getting along with other children	1	Close to average	0	Close to average	No
Kind and helpful behaviour	5	Low	8	Close to average	yes

Table 6-12: Rupert - KIC self-ratings and parent ratings

Problems identified	Self-report	Parent report	Discrepancy
Concentrating	Yes	Yes	No
Getting tired easily	Yes	Yes	No
Remembering things	Yes	Yes	No
Keeping up with the rest of the class	No	N/A	N/A
Planning things, getting organized	Don't know	Yes	Yes
Walking problems	Yes	Yes	No
Writing problems	No	Yes	Yes
Speaking or talking	Yes	Yes	No
Saying sentences so they make sense	Yes	Yes	No
Understanding what other people say	No	Yes	Yes
Reading	Yes	Yes	No
Feelings and behaviour	No	Yes	Yes
KIC Discrepancy Index (higher score=poorer awareness)			4

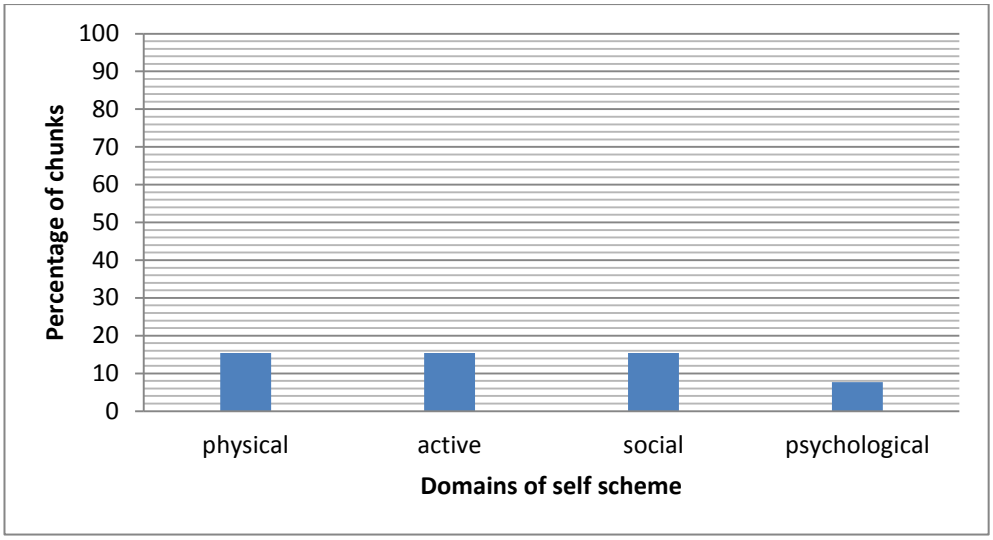

Figure 6-12: Rupert - Percentage of SUI chunks coded to each domain at T1

Table 6-13: Rupert - cooking task scores

Cooking task	
Total error score	45
Goal achieved	With assistance
Recipe located	no
Self-rating before	7
Self-rating after	7 reviewed to 6 (cos it burned)
Researcher rating	4
Discrepancy before-after	No
Discrepancy self-therapist	Yes
Do you think you'll have/you had any particular difficulties?	Before - physical and reading After physical, cognitive and reading

6.8 Discrepancy results – Henry (10 years 1 month at injury; 13 years at recruitment)

6.8.1 Physical domain

Self-others discrepancy: Teacher and self- rating were at the ceiling for "physical appearance". Self-report was also at the ceiling for "athletic competence" and was greater than teacher rating (see Figure 6-13). Self-report identified a problem "getting tired easily" that was not endorsed by parent report. No other physical problems were identified by self or parent report (see Table 6-15). In the Cooking Task physical difficulties were neither anticipated nor observed (see Table 6-16).

Self-norm discrepancy: Self-rating was above the norm value in "athletic competence" and "physical appearance". These items reached the ceiling of 4.0 (see Figure 6-13). The interview data was divided into scoreable chunks and the greatest percentage of chunks were assigned to the physical and active domains (see Figure 6-14). The emergence of some chunks in the social and psychological would be expected at his age (see Damon & Hart, 1988).

6.8.2 Cognitive domain

Self-others discrepancy: Self-report highlighted a difficulty with concentration on one measure but not on the other. Parent report did not identify this as an area of concern (see Tables 6-14 and 6-15). Self and parent report agreed that "remembering things" was difficult and "planning and organising" was not (see Table 6-15). Cognitive difficulties were neither anticipated nor identified on the Cooking Task. The researcher report was lower than the self-report as a result of some cognitive difficulties observed (see Table 6-16).

Self-norm discrepancy: Self-report was **close to average** in "hyperactivity and attentional difficulties" (see Table 6-14). The Cooking Task error score of 28 was at the upper end (see Table 6-16) but within the range of the pilot normative sample (Chevignard, 2010).

6.8.3 Emotional/psychological domain

Self-others discrepancy: Neither self or parent report indicated any difficulties with "feelings and behaviour", "emotional distress" and "overall stress" (see Tables 6-14 and 6-15).

Self-norm discrepancy: Self-report was **close to average** for "emotional distress" and "overall stress" (see Table 6-14). The profile of scoreable chunks from the interview data had no data allocated to the psychological domain. Some emergence of psychological data would be expected at this age (see Figure 6-14).

6.8.4 Social domain

Self-others discrepancy: Self-report for "social acceptance" was above teacher report. Comparative teacher data for other social items was missing (see Figure 6-13). Self-report highlighted a "difficulty getting on with other children" that was not endorsed by the parent-report (see Table 6-14).

Self-norm discrepancy: Self-report of "social acceptance" and "close friendship" reached the ceiling of 4.0. These ratings were higher than the norm value. The self-rating for the item "romantic appeal" however was lower than the norm value (see Figure 6-13). There were some interview chunks assigned to the social domain as expected at this age (see Figure 6-14).

6.8.5 Behavioural domain

Self-others discrepancy: Self-report for the item "behavioural conduct" was slightly higher than the teacher report (see Figure 6-13). There was no reported behavioural difficulties on the other measures by self or parent (see Tables 6-14 and 6-15).

Self-norm discrepancy: Self-report matched the norm value for "behavioural conduct" (see Figure 6-13). Self-report of "behavioural difficulties" and "kind and helpful behaviour" were **close to average** (see Table 6-14).

6.8.6 Communication domain

Self-others discrepancy: Neither self or parent reported any difficulties in this area.

6.8.7 School/learning

Self-others discrepancy: Self-report was greater than the teacher report in the item "scholastic competence" and was close to ceiling. There was no teacher comparison data for "job competence" (see Figure 6-13). Neither self or parent report identified difficulties "keeping up with the rest of the class", "writing" or "reading" (see Table 6-15).

Self-norm discrepancy: Self-report was greater than norm value in the item "scholastic competence" and was close to ceiling (see Figure 6-13).

6.8.8 Henry summary

Henry had some self-awareness that was evident across all of the domains. He was able to recognise difficulties in the emotional/psychological and communication domains, and was reporting at age equivalent level in the cognitive and behavioural

domains. He did not agree with the researcher in the cognitive aspects of the Cooking Task.

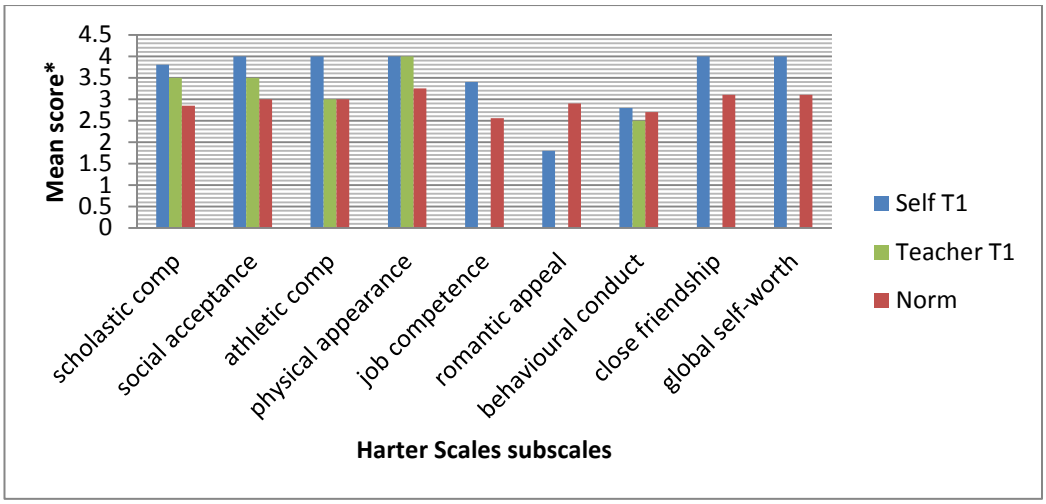

Figure 6-13: Henry - Harter Scales self-rating scores compared to teacher ratings and normative values. *mean scores range 1-4

Table 6-14: Henry - SDQ self-ratings and parent ratings. *Descriptors – very low, low, close to average, high, very high

Discrepancy	Self-report raw scores	Descriptor*	Parent report raw scores	Descriptor	Discrepancy
SDQ overall stress	12	Close to average	9	Close to average	No
Emotional distress	2	Close to average	0	Close to average	No
Behavioural difficulties	2	Close to average	2	Close to average	No
Hyperactivity and attentional difficulties	4	Close to average	5	Close to average	No
Difficulties getting along with other children	4	High	2	Close to average	Yes
Kind and helpful behaviour	8	Close to average	10	Close to average	No

Table 6-15: Henry - KIC self-ratings and parent ratings

Problems identified	Self-rating	Parent rating	Discrepancy
Concentrating	Yes	No	Yes
Getting tired easily	Yes	No	Yes
Remembering things	Yes	Yes	No
Keeping up with the rest of the class	No	No	No
Planning things, getting organized	No	No	No
Walking problems	No	No	No
Writing problems	No	No	No
Speaking or talking	No	No	No
Saying sentences so they make sense	No	No	No
Understanding what other people say	No	No	No
Reading	No	No	No
Feelings and behaviour	No	No	No
KIC Discrepancy Index (higher score=poorer awareness)			2

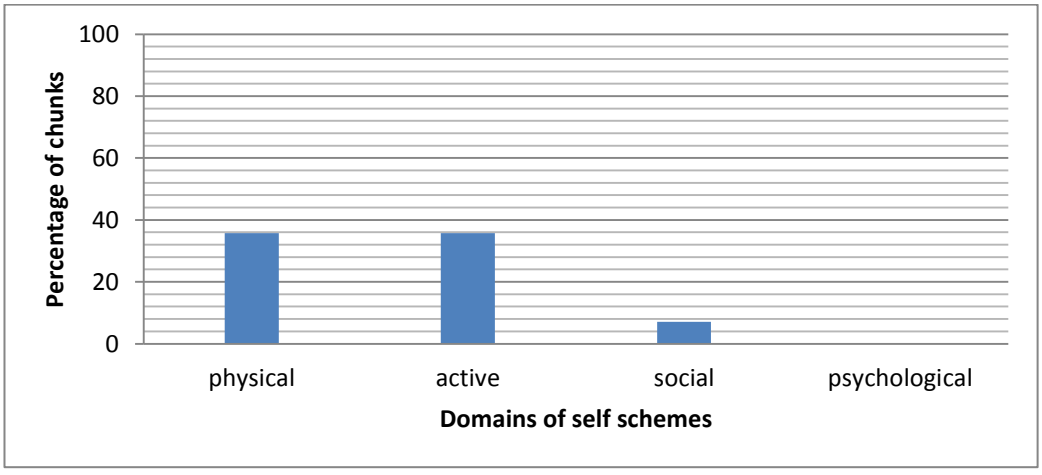

Figure 6-14: Henry - Percentage of SUI chunks coded to each domain at T1

Table 6-16: Henry - cooking task scores

Cooking task	
Total error score	26
Goal achieved	Yes
Recipe located	No
Self-rating before	7
Self-rating after	10
Researcher rating	8
Discrepancy before-after	Yes
Discrepancy self-therapist	Yes
Do you think you'll have/you had any particular difficulties?	Nil

6.9 Discrepancy results – Amelia (16 years 5 months at injury; 19 years at recruitment)

6.9.1 Physical domain

Self-other discrepancy: Parent and young person both recognised fatigue issues. Parent report additionally recognised some "walking" difficulties (see Table 6-18). Self-report anticipated physical difficulties in the Cooking Task that were endorsed by researcher observation. Self-rating was lower than teacher in "physical appearance" but was close to teacher rating in "athletic competence" (see Figure 6-15).

Self-norm discrepancy: Self-rating was above norm in "athletic competence" and below the norm in "physical competence" (see Figure 6-15). There was discrepancy in the profile of scoreable chunks in the interview data from that expected in typical development (see Figure 6-16). Fewer chunks in the physical and active domains and more chunks in the social and psychological domains would be expected (see Damon & Hart, 1988).

6.9.2 Cognitive domain

Self-other discrepancy: Self and parent report recognised the presence of memory difficulties and the absence of other cognitive issues (see Tables 6-17 and 6-18). Amelia recognised that she had not read the instructions sufficiently in the Cooking Task and this had affected the outcome. She recognised that she often rushed into things and rated her performance 4/10 for the task (lower than researcher rating – see Table 6-19).

Self-norm discrepancy: Self-report was **close to average** on the "hyperactivity and attentional difficulty" item (see Table 6-17). The total error score of 16 in the Cooking Task (see Table 6-19) was within the range of the control group in the pilot validation study (Chevignard, 2010).

6.9.3 Emotional/psychological domain

Self-other discrepancy: Self and parent report recognised difficulties in this domain (see Tables 6-17 and 6-18).

Self-norm discrepancy: The SDQ scores are **high** in the "emotional distress" item (see Table 6-17). The profile of the interview chunks was similar to the norm. There was a trend towards items in the psychological domain in keeping with her age (see Figure 6-16).

6.9.4 Social domain

Self-other discrepancy: Although self-report identified some mild difficulties "getting on with other children", the parent report rated them as **high** (see Table 6-17). These social difficulties were not acknowledged in the Harter scales. The self-

rating was above the teacher rating in the “social competence” item. Self-report and teacher report matched on the “close friendship” item (see Figure 6-15).

Self-norm discrepancy: Self-rating was above the norm in “social acceptance”. However, self-report was lower than norm in “romantic appeal” and “close friendship” (see Figure 6-15). The profile of scoreable chunks of interview data (see Figure 6-16) may be expected to have a greater proportion in the social domain at this age (see Damon & Hart 1988)

6.9.5 Behavioural domain

Self-other discrepancy: Parent rating identified “behaviour difficulties” and “kind and helpful behaviour” as problems that were not endorsed by self-report (see Table 6-17). Self-report was greater than teacher report in “behavioural competence” (see Figure 6-15). However, there was agreement between self and parent that “feelings and behaviour” was an area of difficulty (see Table 6-18).

Self-norm discrepancy: Self-report was greater than the norm in “behavioural competence” (see Figure 6-15). Self-report was **close to average** in “behavioural difficulties” and “kind and helpful behaviour” (see Table 6-17).

6.9.6 Communication domain

Self-other discrepancy: Parent report recognised difficulties with speech that self-report did not endorse (see Table 6-18).

6.9.7 School/learning/work

Self-other discrepancy: Teacher report was above the self-report for the item “scholastic competence” but below for “job competence”, but only by a small amount (see Figure 6-15). Parent report recognised “difficulty keeping up with the

rest of the class" that was not endorsed by self-report. Self and parent report agreed that there were no difficulties with reading and writing (see Table 6-18).

Self-norm discrepancy: Self-report was below the norm in the item "scholastic competence" and above the norm in the item "job competence" (see Figure 6-15).

6.9.8 Amelia summary

Amelia had some self-awareness that was evident across all of the domains. There was least agreement in the communication domain and her self-report was not always at an age expected level. She recognised difficulties more readily in the Cooking Task.

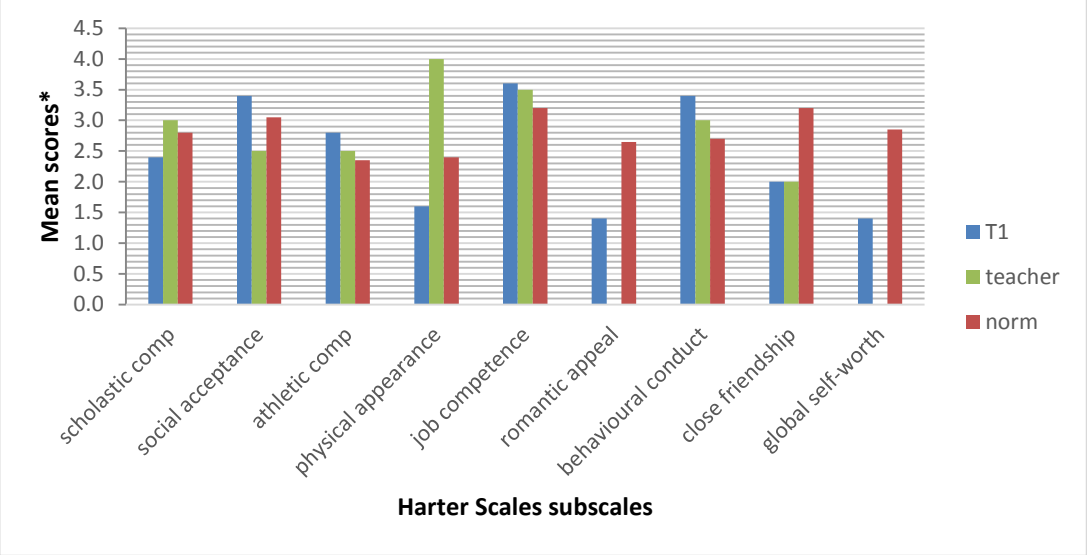

Figure 6-15: Amelia - Harter Scales self-rating scores compared to teacher ratings and normative values. *Mean scores range 1-4

Table 6-17: Amelia - SDQ self-ratings and parent ratings. *Descriptors – very low, low, close to average, high, very high

	Self-report raw scores	Descriptor*	Parent report raw scores	Descriptor	Discrepancy
SDQ overall stress	12	Close to average	16	Slightly raised	yes
Emotional distress	7	Very high	7	Very high	No
Behavioural difficulties	1	Close to average	3	Slightly raised	Yes
Hyperactivity and attentional difficulties	1	Close to average	2	Close to average	No
Difficulties getting along with other children	3	Slightly raised	4	High	Yes
Kind and helpful behaviour	8	Close to average	6	Low	Yes

Table 6-18: Amelia - KIC self and parent ratings

Problems identified	Self-report	Parent report	Discrepancy
Concentrating	No	No	No
Getting tired easily	Yes	Yes	No
Remembering things	Yes	Yes	No
Keeping up with the rest of the class	No	Yes	Yes
Planning things, getting organized	No	No	No
Walking problems	No	Yes	Yes
Writing problems	No	No	No
Speaking or talking	No	Yes	Yes
Saying sentences so they make sense	No	No	No
Understanding what other people say	Yes	Yes	No
Reading	No	No	No
Feelings and behaviour	Yes	Yes	No
KIC Discrepancy Index (higher scores=poorer awareness)			3

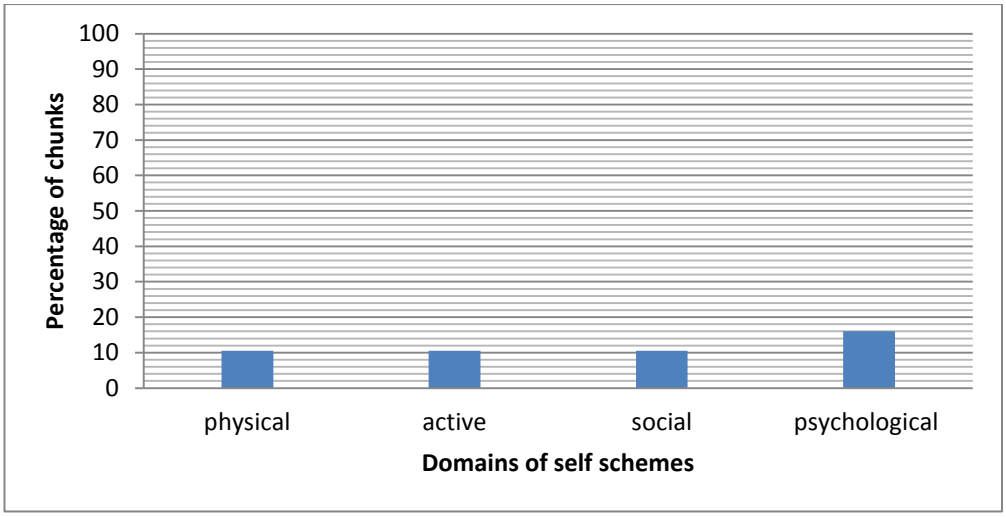

Figure 6-16: Amelia - Percentage of SUI chunks coded to each domain at T1

Table 6-19: Amelia - Cooking task scores

Cooking task	
Total error score	16
Goal achieved	yes
Recipe located	yes
Self-rating before	7
Self-rating after	4
Researcher rating	8
Discrepancy before-after	yes
Discrepancy self-therapist	Yes
Do you think you'll have/you had any particular difficulties?	Before - left arm might be a problem After - didn't read the instructions

6.10 Discrepancy results – Lee (17 years 1 month at injury; 18 years at recruitment)

The parent report data were collected at T2. These data were compared to the self-report data at T2.

6.10.1 Physical domain

Self-others discrepancy: Self-report was greater than the teacher report in "athletic competence" but the reverse was the case in "physical appearance" (see Figure 6-178

17). There was agreement on the physical items in the KIC with parent and self-report (see Table 6-21). Before the cooking task, Lee was able to identify that he would have physical difficulties and these were endorsed by self and researcher after the task.

Self-norm discrepancy: Self-report was lower than the norm value in "athletic competence" and "physical appearance" (see Figure 6-17). The profile of scoreable chunks in the interview data was typical of his age with less chunks assigned to the physical and active domains (see Figure 6-18).

6.10.2 Cognitive domain

Self-others discrepancy: Parent report identified a number of cognitive difficulties and these were endorsed in the self-report – "concentrating", "remembering things", "planning and getting organised" (see Table 6-21). Although both self-report and parent report identified "hyperactivity and attentional difficulties" (see Table 6-20) the parent report rated **very high** compared to **slightly raised** self-report. There was discrepancy between the performance and evaluation of the cooking task. There were 75 errors and the cake was not cooked completely, but the self-rating was 8/10 (see Table 6-22).

Self-norm discrepancy: The "hyperactivity and attentional difficulties" was **slightly raised** compared to norm (see Table 6-20). The 75 errors on the cooking task (see Table 6-21) was outside the range (max=30) of the normative sample (see Chevignard et al 2010)

6.10.3 Emotional/psychological domain

Self-others discrepancy: Self-report highlighted difficulties with "feelings and behaviour" and this was endorsed by the parent report (see Table 6-21). Also self-report highlighted "emotional distress" which was again endorsed by parent. However, the parent report suggested that the difficulties were much greater than the self-report (see Table 6-20),

Self-norm discrepancy: Emotional stress was within norm and "overall stress" was **slightly raised** (see Table 6-20). The profile of scoreable chunks in the interview data (see Figure 6-18) showed a tendency towards the psychological domain but not as a dominant domain that would be expected at his age (see Damon & Hart 1988).

6.10.4 Social domain

Self-others discrepancy: Teacher report for the items "social acceptance" and "close friendship" reached the ceiling of 4.0 and was above the self-rating. Self-report was greater than teacher report for the item "romantic appeal" (see Figure 6-17). There were no reported difficulties in the SDQ by either self or parent (see Table 6-20).

Self-norm discrepancy: Self-report of "social acceptance" and "close friendship" items was below the norm value and "romantic appeal" matched the norm value (see Figure 6-17). The item "difficulties getting along with other children" was **close to average** (see Table 6-20).

6.10.5 Behavioural domain

Self-others discrepancy: Self-report endorsed parent report of difficulties in "feelings and behaviour" item and "behavioural difficulties". However, parent report indicated a greater level of difficulties, **very high** compared to **slightly raised** (see Tables 6-20 and 6-21). Self-report was greater than teacher report of "behavioural conduct" (Harter, see Figure 6-17).

Self-norm discrepancy: Self-report of "behavioural conduct" and "kind and helpful behaviour" were within norm. However, the item "behaviour difficulties" was **slightly raised** (see Figure 6-17 and Table 6-20).

6.10.6 Communication domain

Self-others discrepancy: Self and parent report agreed that this was an area of difficulty (see Table 6- 21).

6.10.7 School/learning

Self-others discrepancy: Self-report of "scholastic competence" and "job competence" were both above the teacher report (see Figure 6-17). Self-report identified "difficulty keeping up with the rest of the class" and "reading" but parent did not comment on these item. Both agree that there were "writing" difficulties" (see Table 6-21).

Self-norm discrepancy: "scholastic competence" and "job competence" were both below the normative value (see Figure 6-17).

6.10.8 Lee summary

Lee had some self-awareness that was evident across all of the domains. He was most able to recognise communication difficulties. His self-report was not at an

age equivalent level, particularly in the cognitive and school/learning domains.

Discrepancy was evident both on the self-report measures and the Cooking Task.

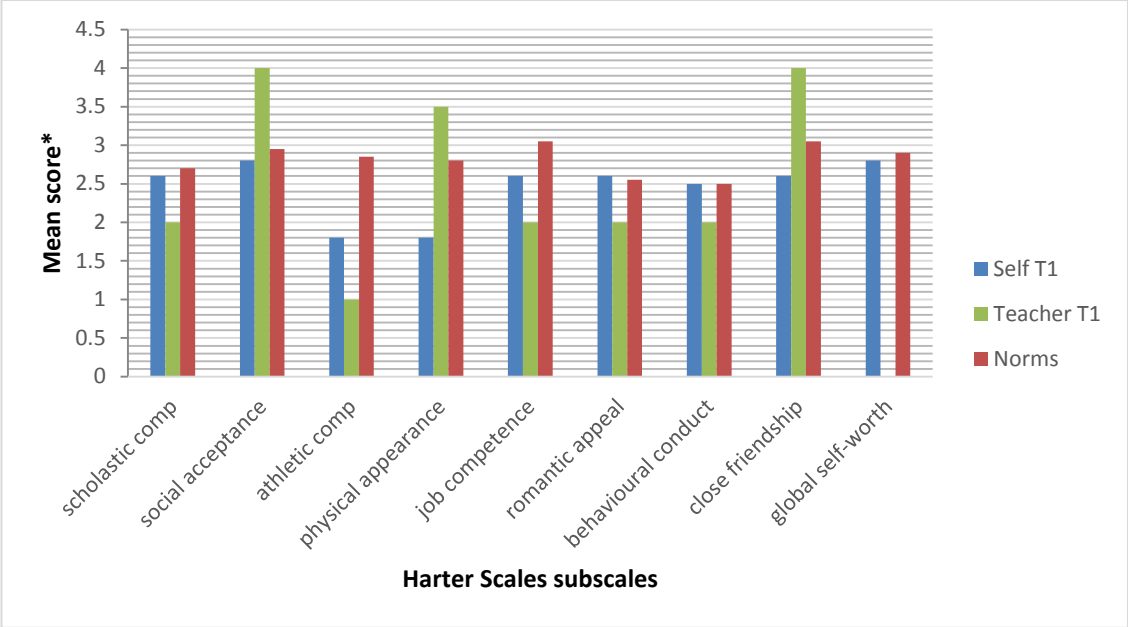

Figure 6-17: Lee - Harter Scales self-rating scores compared to teacher ratings and normative values. *Mean scores range 1-4

Table 6-20: Lee - SDQ self-ratings and parent ratings at T2. *Descriptors – very low, low, close to average, high, very high

	Self-report raw scores	Descriptor*	Parent report raw scores	Compared at T2	Discrepancy
SDQ overall stress	15	Slightly raised	21	Very high	Yes
Emotional distress	3	Close to average	5	High	Yes
Behavioural difficulties	4	Slightly raised	6	Very high	Yes
Hyperactivity and attentional difficulties	6	Slightly raised	9	Very high	Yes
Difficulties getting along with other children	2	Close to average	1	Close to average	No
Kind and helpful behaviour	7	Close to average	9	Close to average	No

Table 6-21: Lee - KIC self-ratings and parent ratings at T2

Problems identified	Self-report	Parent report	Discrepancy
Concentrating	Yes	Yes	No
Getting tired easily	Yes	Yes	No
Remembering things	Yes	Yes	No
Keeping up with the rest of the class	Yes	N/A	N/A
Planning things, getting organized	Yes	Yes	No
Walking problems	Yes	Yes	No
Writing problems	Yes	Yes	No
Speaking or talking	Yes	Yes	No
Saying sentences so they make sense	Yes	Yes	No
Understanding what other people say	Yes	Yes	No
Reading	Yes	N/A	No
Feelings and behaviour	Yes	Yes	No
KIC Discrepancy Index (higher score=poorer awareness)			0

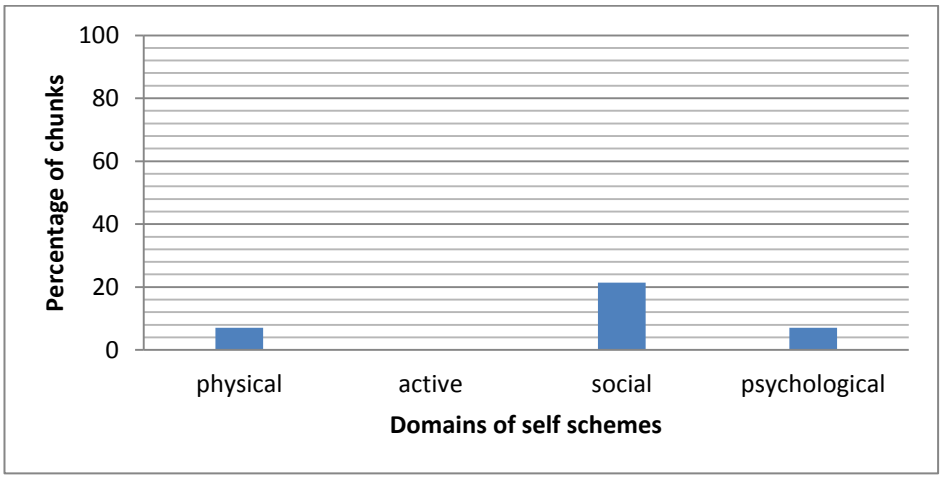

Figure 6-18: Lee - Percentage of SUI chunks coded to each domain at T1

Table 6-22: Lee - Cooking task scores

Cooking task	
Total error score	75
Goal achieved	With assistance - undercooked
Recipe located	No
Self-rating before	6.5
Self-rating after	8
Researcher rating	3
Discrepancy before-after	Yes
Discrepancy self-therapist	Yes
Do you think you'll have/you had any particular difficulties?	Before - keeping things still, no cognitive only physical After - not really any thinking difficulties, otherwise easy, bottle physical, non-slip mat

6.11 Discrepancy results - Robert (13 years 2 months at injury; 17 years at recruitment)

6.11.1 Physical domain

Self-others discrepancy: Self-report identified "walking", "fatigue" and "writing" difficulties that were endorsed by his parent (see Table 6-24). Likewise, before the Cooking Task, he correctly assessed that the task would be physically difficult and chose not to complete it (see Table 6-25). Teacher rating was higher than self-rating in the item "athletic competence" but was closely aligned in the item "physical appearance" (see Figure 6-19).

Self-norm discrepancy: Self-rating was above the norm value for ""physical appearance" and below the norm for "athletic competence", but only by a small ammount (see Figure 6-19). The scoreable chunks from the interview data were assigned only to the psychological domain (see Figure 6-20). Although it is typical to have more chunks in the social and psychological and less chunks in the physical

and active domains with increasing age, it is not typical to have an absence of other data altogether (see Damon & Hart 1988).

6.11.2 Cognitive domain

Self-others discrepancy: There was agreement between self and parent report for "concentrating" but disagreement when rated using the SDQ. Robert identified "hyperactivity and attentional difficulties" as a problem that was not endorsed by his parent (see Tables 6-23 and 6-24). Before the Cooking Task as mentioned above, Robert assessed that the task would be difficult to follow and chose not to complete it.

Self-norm discrepancy: Self-report for "hyperactivity and attentional difficulties" was **slightly raised** (see Table 6-23).

6.11.3 Emotional/psychological domain

Self-others discrepancy: Parent and self-report agreed that there were no problems of "emotional stress" (see Table 6-23) but self-report identified difficulty with "feelings and behaviour" that was not endorsed by parent (see Table 6-24).

Self-norm discrepancy: Self-report was **close to average** for "emotional stress" and "overall stress" (see Table 6-23). The interview transcript was very brief but the script that contained scoreable chunks was assigned to the psychological domain (see Figure6- 20). This pattern was similar to young people of his age.

6.11.4 Social domain

Self-others discrepancy: Self-report reached the ceiling and scored above the teacher report in "social acceptance". Self-rating of "romantic appeal" was greater than the teacher report. However, self-report was lower than teacher report in

"close friendship" (see Figure 6-19). Self and parent report agreed that there was no difficulty "getting on with other children" (see Table 6-23)

Self-norm discrepancy: Self-report was above the norm for "social competence", matched the norm value for "romantic appeal" and was below the norm for "close friendship" (see Figure 6-19). Self-report was **close to average** in the item "getting along with other children" (see Table 6-23).No scoreable chunks from the interview data were assigned to the social domain (see Figure 6-20). This profile differs from the typical trend.

6.11.5 Behavioural domain

Self-others discrepancy: Self-report was lower than the teacher report "behavioural conduct" which was at the ceiling of 4.0 (see Figure 6-19). Self-report highlighted a difficulty with behaviour in the SDQ that was not endorsed by parent report. Conversely in the KIC the parent report indicated a difficulty in "feelings and behaviour" that was not endorsed by the self-report (see Tables 6-23 and 6-24).

Self-norm discrepancy: Self-report matched the norm in "behavioural conduct" (see Figure 6-19). However, self-report was **slightly raised** for the item "behavioural difficulties" and **slightly low** for the item "kind and helpful behaviour" (see Table 6-24)

6.11.6 Communication domain

Self-others discrepancy: Self-report identified communication difficulties in the KIC and these were endorsed by parent report in the item "speaking". There was agreement that there was no difficulty "understanding what other people say" but

disagreed in the item “saying sentences so that they make sense”. Self-report indicated this as an area of difficulty but parent report did not (see Table 6-24).

6.11.7 School/learning

Self-others discrepancy: Teacher report was greater than self-report for “scholastic competence” and reached the ceiling of 4.0 (see Figure 6-19). There was missing data for “job competence”. Self-report and parent report agreed a “difficulty “keeping up with the rest of the class” and “writing” but self-report also identified “reading” difficulties that were not endorsed by parent report (see Table 6-24).

Self-norm discrepancy: Self-rating of “scholastic competence” was lower than the norem and “job competence” was above the norm, but the differences were very small (see Figure 6-19).

6.11.8 Robert summary

Robert had some self-awareness that was evident across all of the domains. He was able to recognise some of his difficulties and the self-report was at an age equivalent level at times, particularly in the emotional/psychological and school/learning domains. He was able to recognise difficulties in the context of the Cooking Task.

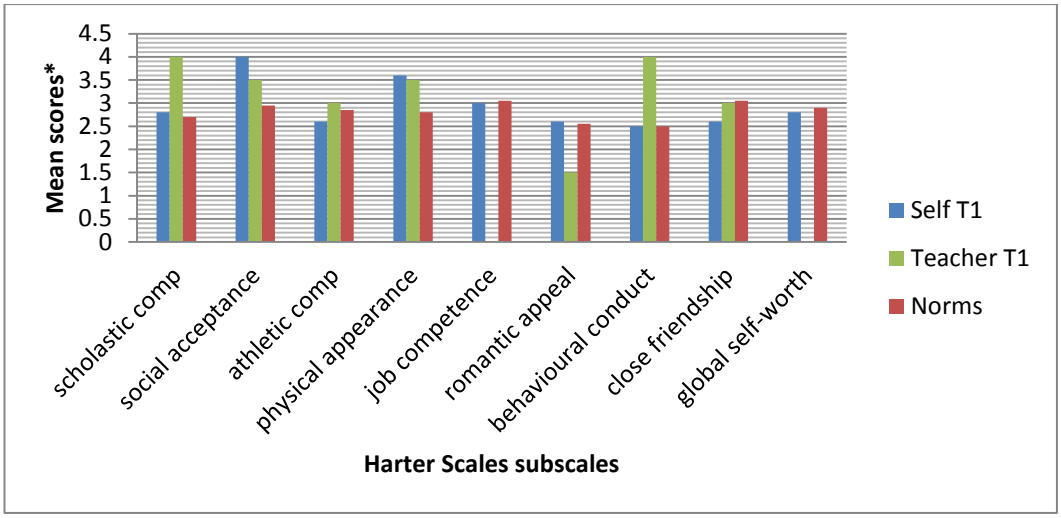

Figure 6-19: Robert - Harter Scales self-rating scores compared to teacher ratings and normative values *mean score range 1-4

Table 6-23: Robert - SDQ self-ratings and parent ratings. ***Descriptors – very low, low, close to average, high, very high**

	Self-report raw scores	Descriptor *	Parent report raw scores	Descriptor	Discrepancy
SDQ overall stress	11	Close to average	8	Close to average	No
Emotional distress	0	Close to average	0	Close to average	No
Behavioural difficulties	4	Slightly raised	2	Close to average	Yes
Hyperactivity and attentional difficulties	6	Slightly raised	5	Close to average	Yes
Difficulties getting along with other children	1	Close to average	1	Close to average	No
Kind and helpful behaviour	6	Slightly low	9	Close to average	yes

Table 6-24: Robert - KIC self and parent ratings

Problems identified	Self	Parent	Discrepancy
Concentrating	Yes	Yes	No
Getting tired easily	Yes	Yes	No
Remembering things	No	Yes	Yes
Keeping up with the rest of the class	Yes	Yes	No
Planning things, getting organized	Yes	Yes	No
Walking problems	Yes	Yes	No
Writing problems	Yes	Yes	No
Speaking or talking	Yes	Yes	No
Saying sentences so they make sense	Yes	No	Yes
Understanding what other people say	No	No	No
Reading	No	Yes	Yes
Feelings and behaviour	No	Yes	Yes
KIC Awareness Discrepancy Index (higher scores= poorer awareness			**4**

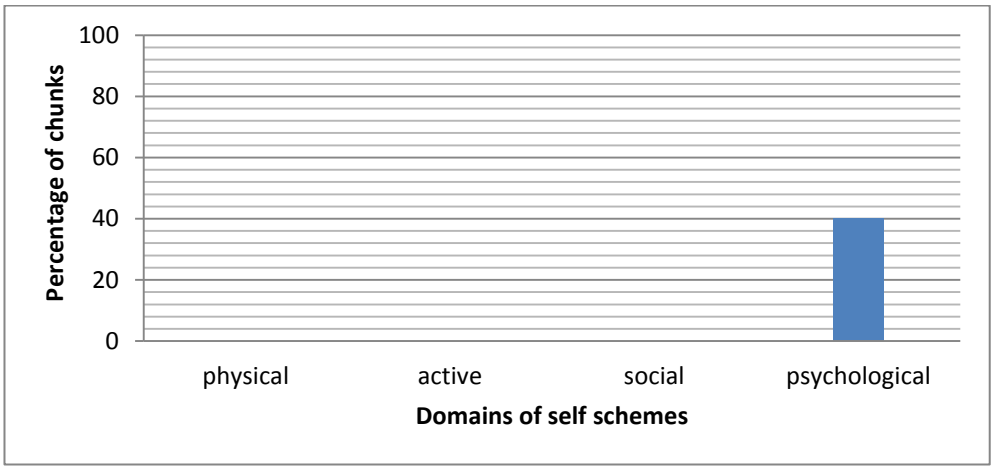

Figure 6-20: Robert - Percentage of SUI chunks coded to each domain at T1

Table 6-25: Robert - Cooking task scores

Cooking task	
Self-rating before	1/10
Self-rating after	N/A
Researcher rating	Self-assessed as too difficult and chose not to complete
Discrepancy before-after	
Discrepancy self-therapist	
Do you think you'll have/you had any particular difficulties?	

6.12 Discrepancy results –Tracey (14 years 11 months at injury; 19 years at recruitment)

6.12.1 Physical domain

Self-others discrepancy: Self-report was greater than the teacher report in the item "athletic competence". However, self-report was lower than teacher report in "physical appearance" which was at the ceiling of 4.0 (see Figure 6-21). There was discrepancy between the self and parent report in the KIC. Parent report identified "getting tired easily", "writing" and "walking" difficulties. "Writing" difficulties were not endorsed by the self-report (see Table 6-27). Before the Cooking Task, Tracey was able to identify that there may be some physical difficulties with "two-handed stuff" (see Table 6-28). There were observable difficulties as predicted but she did not report them afterwards.

Self-norm discrepancy: Self-report was below norm for "physical appearance" and "athletic competence" (see Figure 6-21). The scoreable chunks from the interview data do not correspond to her age (see Figure 6-22). Fewer chunks in the active domain would be expected (see Damon & Hart 1988).

6.12.2 Cognitive domain

Self-others discrepancy: There was no discrepancy between self and parent report on the KIC and SDQ. Both Tracey and her parent identified where difficulties were in this domain (see Tables 6-26 and 6-27). No cognitive difficulties were anticipated before the Cooking Task nor were they reported afterwards (see Table 6-28).

Self-norm discrepancy: self-report of "hyperactivity and attentional difficulties" was **close to average** (see Table 6-26). The total error score on the Cooking Task was 15 (see Table 6-28) which was within the range of the typically developing pilot group (Chevignard, 2010)

6.12.3 Emotional/psychological domain

Self-others discrepancy: Both self and parent report identify difficulty with "feelings and behaviour" (see Table 6-27). However, Tracey reports "emotional distress" that is not endorsed by parent report and parent report of "overall stress" is **slightly raised** compared to self-report (see Table 6-26).

Self-norm discrepancy: Self-report is **slightly raised** for "emotional distress" (see Table 6-26). The scoreable chunks from the interview data was not at the age expected level (see Figure 6-22). More chunks in the psychological domain would be expected.

6.12.4 Social domain

Self-others discrepancy: Self-report was greater than teacher report in "social competence", "close friendship" and "romantic appeal" (see Figure 6-21). Parent report identified "difficulties getting on with other children" which was not endorsed in the self-report (see Table 6-26).

Self-norm discrepancy: Self-report was above the norm in "social competence", "close friendship" and "romantic appeal" (see Figure 6-21). Self-report was **close to average** for "getting along with other children" (see Table 6-26). There were some scoreable chunks allocated to the social domain as expected at her age (see Figure 6-22).

6.12.5 Behavioural domain

Self-others discrepancy: Self-report was close to teacher report for "behavioural conduct" (see Figure 6-19). Parent reported difficulty with "kind and helpful behaviour" that was not endorsed in the self-report (see Table 6-26). However, there was agreement in the item difficulty with feelings and behaviour between self and parent report (see Table 6-27).

Self-norm discrepancy: Self-report was below the norm in "behavioural conduct", although by a small amount, and **close to average** in "behavioural difficulties" (see Figure 6-21 and Table 6-26)

6.12.6 Communication domain

Self-others discrepancy: Neither self or parent report identified difficulties in this domain (see Table 6-27).

6.12.7 School/learning

Self-others discrepancy: Self-rating for "scholastic competence" was lower than the teacher report. There was missing data for job competence and no comparison was possible (see Figure 6-21). There was agreement between self and parent report regarding "difficulties keeping up with the rest of the class" but

disagreement with “reading” and “writing”. Parent report identified difficulties that were not endorsed in self-report (see Table 6-27).

Self-norm discrepancy: Self-report of “scholastic competence” was below the norm value but only by a small amount, and “job competence was below norm (see Figure 6-21).

6.12.8 Tracey summary

Tracey had some self-awareness that was evident across all of the domains. She was able to identify some of her difficulties in the self-report, particularly in the cognitive and communication domains and Cooking Task. The self-report was at an age equivalent level at times, notably in the cognitive and behavioural domains.

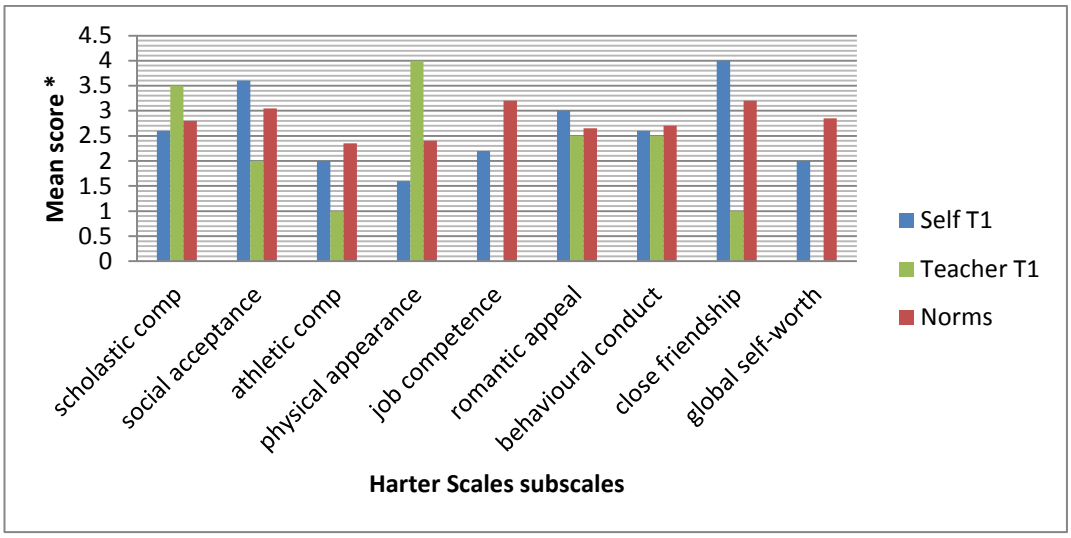

Figure 6-21: Tracey - Harter Scales self-rating scores compared to teacher rating and normative values. *mean scores range 1-4

Table 6-26: Tracey - SDQ self-ratings and parent ratings. *Descriptors – very low, low, close to average, high, very high

	Self-report raw score	Descriptor*	Parent report raw score	Descriptor	Discrepancy
SDQ overall stress	11	Close to average	15	Slightly raised	Yes
Emotional distress	5	Slightly raised	3	Close to average	Yes
Behavioural difficulties	3	Close to average	4	High	Yes
Hyperactivity and attentional difficulties	3	Close to average	4	Close to average	No
Difficulties getting along with other children	0	Close to average	4	High	Yes
Kind and helpful behaviour	10	Close to average	7	Slightly low	Yes

Table 6-27: Tracey - KIC self and parent ratings

Problems identified	Self-report	Parent report	Discrepancy
Concentrating	Yes	Yes	No
Getting tired easily	Yes	Yes	No
Remembering things	No	No	No
Keeping up with the rest of the class	Yes	Yes	No
Planning things, getting organized	Yes	Yes	No
Walking problems	Yes	Yes	No
Writing problems	No	Yes	Yes
Speaking or talking	No	No	No
Saying sentences so they make sense	No	No	No
Understanding what other people say	No	No	No
Reading	No	Yes	Yes
Feelings and behaviour	Yes	Yes	No
KIC Discrepancy Index (higher score=poorer awareness			2

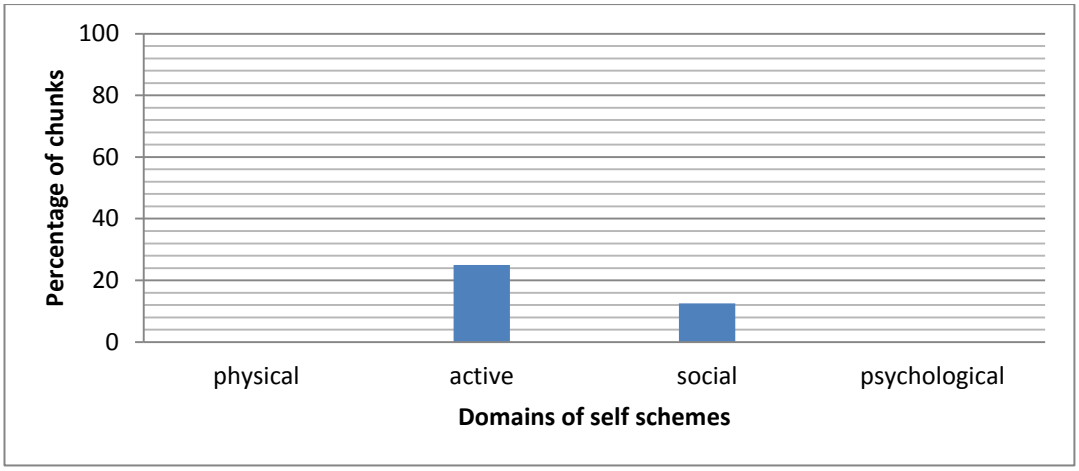

Figure 6-22: Tracey - Percentage of SUI chunks coded to each domain at T1

Table 6-28: Tracey - Cooking task scores

Cooking task	
Total error score	15
Goal achieved	yes
Recipe located	No-self corrected
Self-rating before	4
Self-rating after	5
Researcher rating	8
Discrepancy before-after	yes
Discrepancy self-therapist	yes
Do you think you'll have/you had any particular difficulties?	Before – two-handed things After – cognitive stuff was fine, measurements not

6.13 Discrepancy results – Debbie (17 years at injury; 18 years at recruitment)

6.13.1 Physical domain

Self-others discrepancy: Self-rating and teacher rating were the same for "athletic competence" but teacher rating was higher than self-rating for "physical appearance" and reached the ceiling of 4.0 (see Figure 6-23). Parent rating reported difficulty in "walking", "writing" and "getting tired easily". "Walking" and "writing" were not endorsed in the self-report (see Table 6-30). No physical

difficulties were anticipated, reported or observed for the Cooking Task (see Table 6-31).

Self-norm discrepancy: Self-rating was lower than the norm value for "athletic competence" and above norm for "physical appearance" (see Figure 6-23). The profile of scoreable chunks in the interview data had fewer chunks in the physical and active domains (see Figure 6-24) as expected at this age (see Damon & Hart 1988).

6.13.2 Cognitive domain

Self-others discrepancy: Before the Cooking Task the only anticipated difficulty highlighted was that there would be unfamiliarity with the recipe (see Table 6-31). There was little discrepancy between self-rating (9/10) and researcher rating (8/10). Parent report highlighted "hyperactivity and attentional difficulties" that was not endorsed in the self-report (see Table 6-29). Self and parent report agreed that "concentrating" and "remembering things" were difficult. They also agreed that "planning and organising" was not a problem (see Table 6-30).

Self-norm discrepancy: Self report of "hyperactivity and attentional difficulties" was close to average (see Table 6-29). The number of errors (see Table 6-31) was within the range of the pilot control group (28 errors, Chevignard, 2010).

6.13.3 Emotional/psychological domain

Self-others discrepancy: Parent report of "emotional distress" was **high** compared to the **average** rating of self-report (see Table 6-29). Parent and self-report agreed difficulties with "feelings and behaviour" (see Table 6-30).

Self-norm discrepancy: Self-report for "emotional distress" was **close to average** (see Table 6-29). However, the percentage of scoreable chunks allocated to the psychological domain was less than expected at her age (see Figure 6-24).

6.13.4 Social domain

Self-others discrepancy: Self-rating was lower than teacher rating for "social competence", "close friendship" and "romantic appeal" (see Figure 6-23). Parent report identified "difficulties getting on with other children" that was not endorsed by self-report (see Table 6-29).

Self-norm discrepancy: Self-ratings were above the norm value in "social competence", "close friendship" and "romantic appeal" (see Figure 6-23). Self-report was within **average** range for "getting along with other children" (see Table 6-29). The interview data (SUI) was divided into scoreable chunks. The majority of the data was scored to the social domain (see Figure 6-24) which was similar to aged matched norms (see Damon & Hart 1988).

6.13.5 Behavioural domain

Self-others discrepancy: The parent report for "kind and helpful behaviour" indicated a difficulty that was not endorsed in the self-report (see Table 6-29). Self and parent report agreed that "feelings and behaviour" was an area of difficulty (see Table 6-30). Self-report was greater than teacher report for "behavioural conduct" (see Figure 6-23).

Self-norm discrepancy: self-report was **close to average** for "kind and helpful behaviour" and "behavioural conduct" (see Figure 6-23 and Table 6-29).

6.13.6 Communication domain

Self-others discrepancy: Parent report identified difficulty "talking" but this was not endorsed in the self-report. However, self-and parent report agreed that there were difficulties "saying sentences so that they made sense" and "understanding what other people say" (see Table 6-30).

6.13.7 School/learning

Self-others discrepancy: Self-rating was less than teacher rating for "scholastic competence", although only by a small amount. There was no data to compare for "job competence" or "keeping up with the rest of the class" (see Figure 6-23 and Table 6-30). Parent report identified difficulty with "reading" and "writing". These were not endorsed by self-report (see Table 6-30).

Self-norm discrepancy: Self-rating of "scholastic competence" was below the normative value. Self-rating of "job competence" was above the norm value (see Figure 6-23).

6.13.8 Debbie summary

Debbie had some self-awareness that was evident across all domains. There were no areas where she was in agreement with the report of others. Her self-report was at an age equivalent level at times. There was little discrepancy in the Cooking Task.

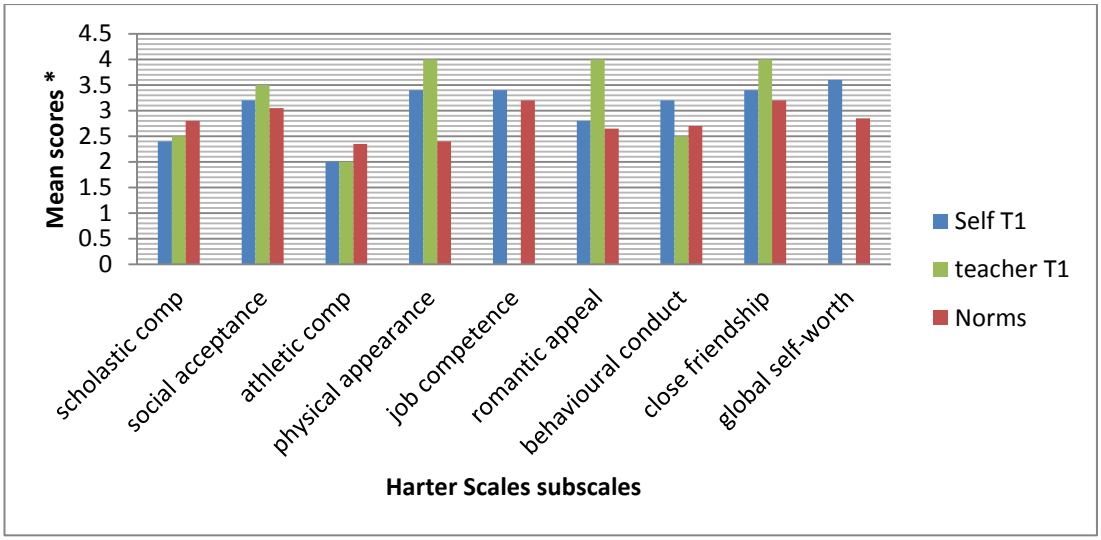

Figure 6-23: Debbie - Harter Scales self-rating scores compared to teacher ratings and normative values. *mean scores range 1-4

Table 6-29: Debbie - SDQ self-rating and parent rating. *Descriptors – very low, low, close to average, high, very high

	Self-report raw scores	Descriptor*	Parent report raw scores	Descriptor	Discrepancy
SDQ overall stress	10	Close to average	26	Very high	Yes
Emotional distress	2	Close to average	7	Very high	Yes
Behavioural difficulties	3	Close to average	7	Very high	Yes
Hyperactivity and attentional difficulties	4	Close to average	8	High	Yes
Difficulties getting along with other children	1	Close to average	4	High	Yes
Kind and helpful behaviour	7	Close to average	7	Slightly low	Yes

Table 6-30: Debbie - KIC self-rating and parent ratings

Problems identified	Self-report	Parent report	Discrepancy
Concentrating	Yes	Yes	No
Getting tired easily	Yes	Yes	No
Remembering things	Yes	Yes	No
Keeping up with the rest of the class	Yes	N/A	N/A
Planning things, getting organized	No	No	No
Walking problems	No	Yes	Yes
Writing problems	No	Yes	Yes
Speaking or talking	No	Yes	Yes
Saying sentences so they make sense	Yes	Yes	No
Understanding what other people say	Yes	Yes	No
Reading	No	Yes	Yes
Feelings and behaviour	Yes	Yes	No
KIC Discrepancy Index (higher score = poorer awareness)			4

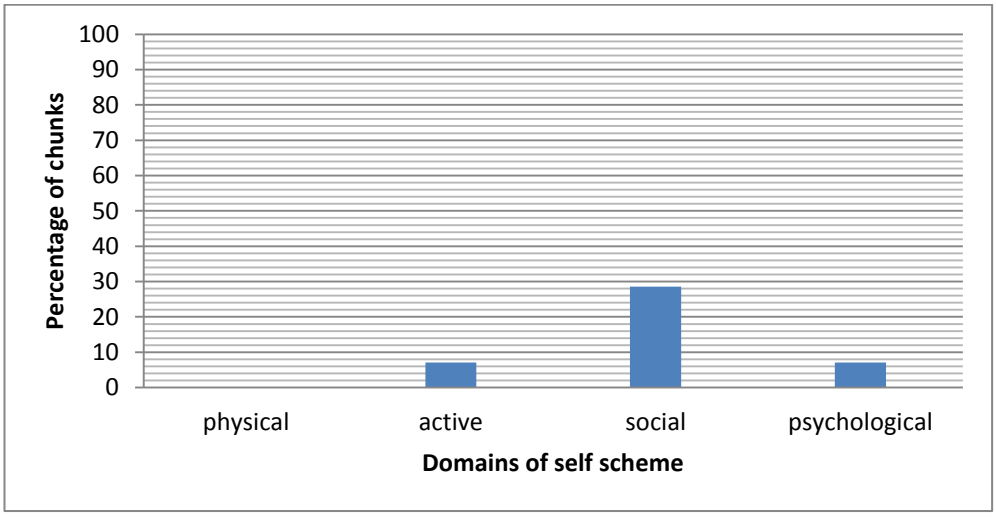

Figure 6-24: Debbie - Percentage of SUI chunks coded to each domain at T1

Table 6-31: Debbie - Cooking task scores

Cooking task	
Total error score	28
Goal achieved	Yes
Recipe located	No
Self-rating before	8
Self-rating after	9
Researcher rating	8
Discrepancy before-after	yes
Discrepancy self-therapist	yes
Do you think you'll have/you had any particular difficulties?	Before - unfamiliar

6.14 Discrepancy results – Stuart (13 years 10 months at injury; 17 years at recruitment)

6.14.1 Physical domain

Self-others discrepancy: Teacher report was greater than the self-report in the "athletic competence" and "physical appearance" items (see Figure 6-25). While parent and self-report agreed that there were no "walking" difficulties and that there were "writing" difficulties, self-report identified "getting tired easily" that was not endorsed by the parent report (see Table 6-33). Stuart also identified some pouring difficulties during the Cooking Task (see Table 6-34).

Self-norm discrepancy: Self-report was below the norm value in items "athletic competence" and "physical appearance" (see Figure 6-25). The scoreable chunks from the interview data was assigned less to the physical and active domains (see Figure 6-26) as expected at this age (see Damon & Hart 1988).

6.14.2 Cognitive domain

Self-others discrepancy: Self-report identified **slightly raised** "hyperactivity and attentional difficulties"; and difficulty "planning and organising" and "concentrating" that were not endorsed by the parent report (see Tables 6-32 and 6-33). However, the parent and self-report both identified difficulties "remembering things". Before the Cooking Task Stuart identified that he may not remain on task long enough, affecting the final product. However, he did not report any cognitive difficulties afterwards and agreed a score of 8/10 with the researcher rating (see Table6- 34).

Self-norm discrepancy: Self-report of "hyperactivity and attentional difficulties" was **slightly raised** compared to norm (see Table 6-32) Stuart had a total error score of 29 on the Cooking Task, which was within the range of the control group in the pilot validation study (see Chevignard, 2010).

6.14.3 Emotional/psychological domain

Self-others discrepancy: Self and parent report agree difficulties with "feelings and behaviour" and agree no problems with "emotional stress" (see Tables 6-32 and 6-33).

Self-norm discrepancy: Self-report of "emotional stress" and "overall stress" was **close to average** (see Table 6-32). There were less scoreable chunks of interview data assigned to the psychological domain than expected at this age (see Figure 6-26).

6.14.4 Social domain

Self-others discrepancy: Self-report was below teacher report for "social acceptance" and "romantic appeal" and greater than teacher report for "close friendship", although only by a small amount (see Figure 6-25). Although self-report and parent report identified difficulties "getting on with other children", the self-report scored this as **very high** and the parent scored as **high** (see Table 6-32).

Self-norm discrepancy: Self-rating of "social competence" and "close friendship" were below the norm value. Self-rating of "romantic appeal" matched the norm (see Figure 6-25). Self-rating of "Difficulties getting on with other children" was **very high** (see Table 6-32). The scoreable chunks in the interview data were mostly allocated to the social domain as expected at this age (see Figure 6-26).

6.14.5 Behavioural domain

Self-others discrepancy: Self-report identified difficulty with "kind and helpful behaviour" that was not endorsed in the parent report. Both self and parent report identified difficulty with "feelings and behaviour" and neither identified "behaviour difficulties" as a problem (see Tables 6-32 and 6-33). Self and teacher report were close for the item "behavioural conduct" (see Figure 6-25).

Self-norm discrepancy: Self-report of "behavioural conduct" was below the norm but only by a small amount, and "behavioural difficulties" were **close to average** (see Figure 6-25 and Table 6-32). However, self-report of "kind and helpful behaviour" was slightly low (see Table 6-32).

6.14.6 Communication domain

Self-others discrepancy: No issues were highlighted in this domain by either parent or self-report (see Table 6-33).

6.14.7 School/learning

Self-others discrepancy: Self-rating of "scholastic competence" was below teacher report (see Figure 6-25). Both parent and self-report highlighted difficulties "keeping up with the rest of the class" and "writing" whilst agreeing that there were no "reading" difficulties (see Table 6-33).

Self-norm discrepancy: Self-rating of "scholastic competence" was below norm. There was no data to compare for "job competence" (see Figure 6-25).

6.14.8 Stuart summary

Stuart had some self-awareness that was evident across all of the domains. He was able to recognise difficulties in the emotional/psychological and communication domains, and his self-report was at an age equivalent level at times. There was agreement between self and researcher report on the Cooking Task.

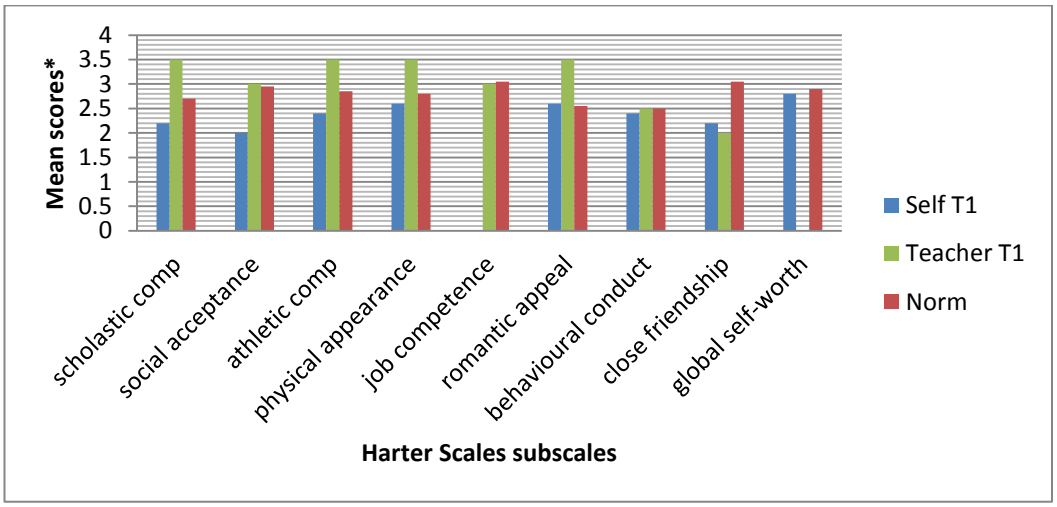

Figure 6-25: Stuart - Harter Scales self-report scores compared to teacher report and normative values. *mean scores range 1-4

Table 6-32: Stuart - SDQ self-ratings and parent ratings. *Descriptors – very low, low, close to average, high, very high

	Self-report raw scores	Descriptor*	Parent report raw scores	Descriptor	Discrepancy
SDQ overall stress	14	Close to average	11	Close to average	No
Emotional distress	1	Close to average	2	Close to average	No
Behavioural difficulties	2	Close to average	1	Close to average	No
Hyperactivity and attentional difficulties	6	Slightly raised	4	Close to average	Yes
Difficulties getting along with other children	5	Very high	4	High	Yes
Kind and helpful behaviour	6	Slightly low	8	Close to average	Yes

Table 6-33: Stuart - KIC self and parent ratings

Problems identified	Self-report	Parent report	Discrepancy
Concentrating	Yes	No	Yes
Getting tired easily	Yes	No	Yes
Remembering things	Yes	Yes	No
Keeping up with the rest of the class	Yes	Yes	No
Planning things, getting organized	Yes	No	Yes
Walking problems	No	No	No
Writing problems	Yes	Yes	No
Speaking or talking	No	No	No
Saying sentences so they make sense	No	No	No
Understanding what other people say	No	Yes	Yes
Reading	No	No	No
Feelings and behaviour	Yes	Yes	No
KIC Discrepancy Index (higher scores = poorer awareness			4

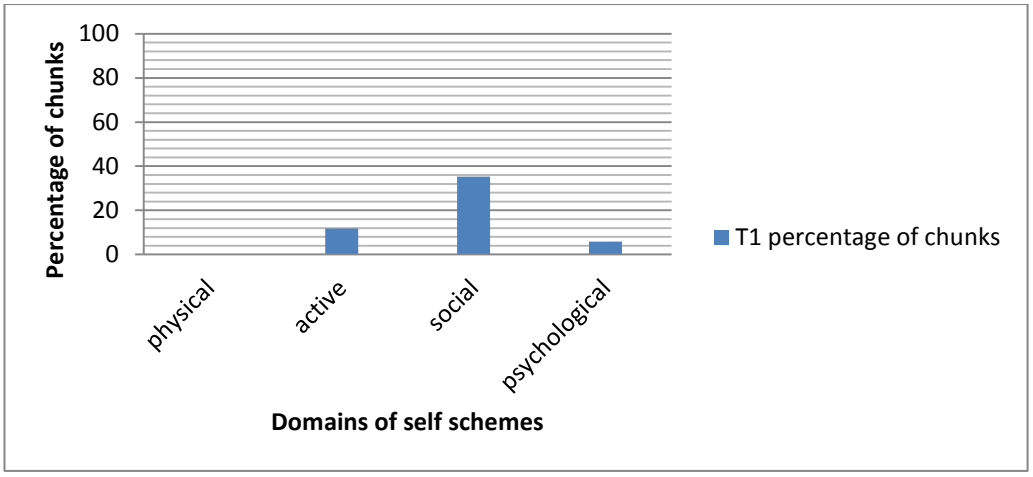

Figure 6-26: Stuart - Percentage of SUI chunks coded to each domain at T1

Table 6-34: Stuart - Cooking Task scores

Cooking task	
Total error score	29
Goal achieved	Yes
Recipe located	No
Self-rating before	7
Self-rating after	8
Researcher rating	8
Discrepancy before-after	yes
Discrepancy self-therapist	no
Do you think you'll have/you had any particular difficulties?	Before – I get bored and impatient, mixing "that'll do" so might not turn out so well After - pouring

6.15 Discrepancy results – Rachel (14 years 6 months at injury; 16 years at recruitment)

6.15.1 Physical domain

Self-others discrepancy: Self-rating was below teacher rating in "athletic competence" and "physical appearance" (see Figure 6-27). Parent report identified "getting tired easily", "walking" and "writing" as difficulties. These were not endorsed in self-report (see Table 6-36).

Self-norm discrepancy: Self-rating was below the norm values in "athletic competence" and "physical appearance" (see Figure 6-27). There was a greater proportion of interview data assigned to the physical/active domain (see Figure 6-28) than expected at her age (see Damon & Hart 1988).

6.15.2 Cognitive domain

Self-others discrepancy: Self-report identified difficulties "remembering" and "concentrating" and these were endorsed by mother. However, self-report did not identify difficulties with "planning and organising" or "hyperactivity and attentional difficulties" that were highlighted by parent report (see Tables 6-35 and 6-36). Self-report did not predict or recognise any cognitive difficulties in the Cooking Task (see Table 6-37). Memory and self-monitoring difficulties were observed throughout the task.

Self-norm discrepancy: Self-report of "hyperactivity and attentional difficulties" were **close to average** (see Table 6-35). The number of errors in the cooking tasks (see Table 6-37) was greater than the norm sample (see Chevignard, 2010).

6.15.3 Emotional/psychological domain

Self-others discrepancy: Self-report and parent report both indicated difficulties with "feelings and behaviour" but no "emotional distress" (see Tables 35 and 36). However, parent report identified "overall stress" higher than self-report (see Table 6-35).

Self-norm discrepancy: Self-report was **close to average** for "emotional distress" and "overall stress" (see Table 6-35).There was a proportion of interview data

assigned to the psychological domain that would be typical of Rachel's age (see Figure 6-28).

6.15.4 Social domain

Self-others discrepancy: Self-report was below teacher report in "social competence". However, in "close friendship" and "romantic appeal" the self-report was greater than teacher report (see Figure 6-27). Additionally parent report highlighted "difficulties getting on with other children" that was not endorsed in self-report (see Table 6-35).

Self-norm discrepancy: Self-report was equal to the norm value in "social competence" and below the norm in "romantic appeal". Self-report reached the ceiling in "close friendship" and was greater than the norm (see Figure 6-27). A proportion of the scoreable chunks in the interview data were allocated to the social domain as expected at this age (see Figure 6-28).

6.15.5 Behavioural domain

Self-others discrepancy: Both self-report and parent report indicated "behaviour difficulties" and a reduction in "kind and helpful behaviour" but parent report indicated that the problem was more severe (see Table 6-35). Self-rating was lower than teacher rating for "behavioural conduct" (see Figure 6-27). Self and parent report agreed that there are difficulties with "feelings and behaviour" (see Table 6-36).

Self-norm discrepancy: Self-report was below the norm for "behavioural difficulties"; "kind and helpful behaviour" and "behavioural conduct" (see Figure 6-27 and Table 6-35).

6.15.6 Communication domain

Self-others discrepancy: Self-report did not identify any difficulties that were highlighted by parent report (see Table 6-36).

6.15.7 School/learning

Self-others discrepancy: Teacher report was greater than the self-report for "scholastic competence". There was no data to compare for "job competence" (see Figure 6-27). Self and parent report highlighted difficulties "keeping up with the rest of the class" and agreed there were no "reading" difficulties. However, parent report recognised "writing" problems that were not endorsed in self-report (see Table 6-36).

Self-norm discrepancy: Self-report of "scholastic competence" was higher than the norm value (see Figure 6-27).

6.15.8 Rachel summary

Rachel had self-awareness that was only evident across some of the domains. She was only able to identify difficulties in four of the seven domains and her self-report was only at an age matched level in the emotional/psychological domain. There was no evidence of age-matched self-reporting in three of the six domains. She found it equally difficult to identify difficulties in the Cooking Task.

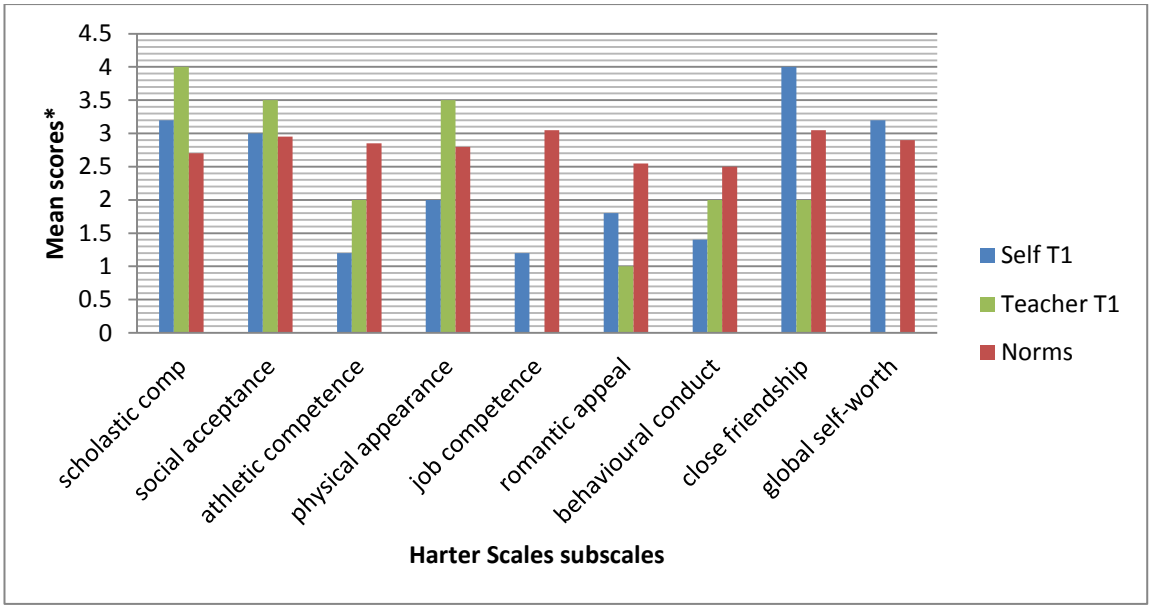

Figure 27: Rachel - Harter Scales self-rating scores compared to teacher ratings and normative values. *mean scores range 1-4

Table 6-35: Rachel - SDQ self-ratings and parent ratings. *Descriptors – very low, low, close to average, high, very high

	Self-report raw scores	Descriptor*	Parent report	Descriptor	Discrepancy
SDQ overall stress	8	Close to average	18	High	Yes
Emotional distress	1	Close to average	3	Close to average	No
Behavioural difficulties	4	Slightly raised	4	High	Yes
Hyperactivity and attentional difficulties	3	Close to average	8	High	Yes
Difficulties getting along with other children	0	Close to average	3	Slightly raised	Yes
Kind and helpful behaviour	5	Low	5	Very low	Yes

Table 6-36: Rachel - KIC self and parent ratings

Problems identified	Self-report	Parent report	Discrepancy
Concentrating	Yes	Yes	No
Getting tired easily	No	Yes	Yes
Remembering things	Yes	Yes	No
Keeping up with the rest of the class	Yes	Yes	No
Planning things, getting organised	No	Yes	Yes
Walking problems	No	Yes	Yes
Writing problems	No	Yes	Yes
Speaking or talking	No	Yes	Yes
Saying sentences so they make sense	No	Yes	Yes
Understanding what other people say	Yes	Yes	No
Reading	No	No	No
Feelings and behaviour	Yes	Yes	No
KIC Discrepancy Index (higher scores = poorer awareness)			6

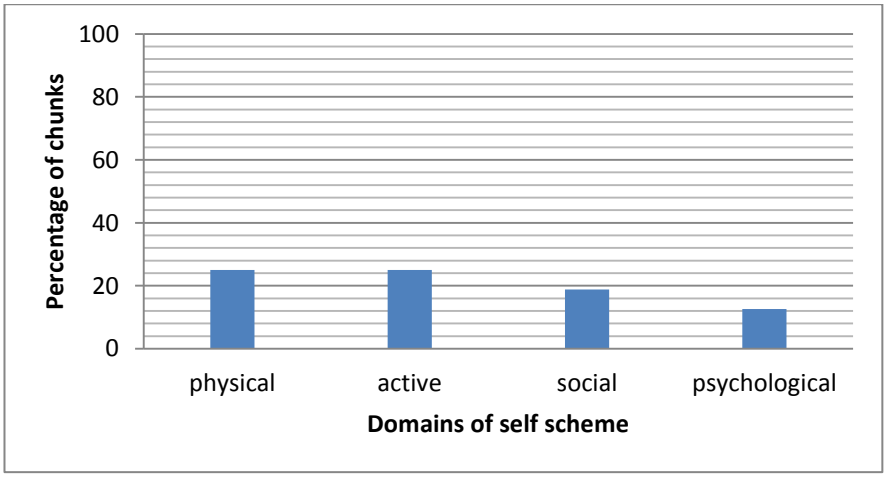

Figure 28: Rachel - Percentage of SUI chunks coded to each domain at T1

Table 6-37: Rachel - Cooking task scores

Cooking task	
Total error score	30
Goal achieved	Yes
Recipe located	No
Self-rating before	7
Self-rating after	10
Researcher rating - after	6
Discrepancy before-after	Yes
Discrepancy self-therapist	Yes
Do you think you'll have/you had any particular difficulties?	Before - no problems/difficulties, no particular reason for predicting 7 After - no problems

6.16 Discrepancy results -Dan (9 years 6 months at injury; 10 years at recruitment)

The discrepancy across domains could not be fully evaluated due to missing data. Researcher observed anxiety during the visits and mother report indicated a number of difficulties in this domain. Dan was unable to complete the KIC during the first visit for comparison and was too young to complete SDQ comparison data.

6.16.1 Physical domain

Self-others discrepancy: Self-rating in "physical appearance" and "athletic competence" were both higher than teacher report (see Figure 6-29). He did not report or experience any physical difficulties in the Cooking Task (see Table 6-40).

Self-norm discrepancy: Self-ratings in "physical appearance" and "athletic competence" were both below norm (see Figure 6-29). The interview data had more scoreable chunks in the physical domain with some in the active and social domain (see Figure 6-30). This was typical of a child of Dan's age (see Damon & Hart).

6.16.2 Cognitive domain

Self-others discrepancy: Dan had difficulty attending to the Cooking Task and following the instructions. He did not recognise these cognitive difficulties in his prediction or evaluation (see Table 6-40).

Self-norm discrepancy: In the Cooking Task Dan had a total error score (see Table 6-40) that was greater than the normative sample (see Chevignard, 2010).

6.16.3 Emotional/psychological domain

Self-others discrepancy: missing data

Self-norm discrepancy: There were no scoreable chunks from the interview data allocated to the psychological domain. This is typical of this age (see Figure 6-30).

6.16.4 Social domain

Self-others discrepancy: Self-report was greater than teacher report in "social acceptance" (see Figure 6-29).

Self-norm discrepancy: Self-report was greater than norm in "social acceptance", although only by a small amount (see Figure 29). There was evidence of some scoreable chunks from interview data allocated to the social domain as expected at this age (see Figure 6-30).

6.16.5 Behavioural domain

Self-others discrepancy: Self-report was higher than teacher report in "behavioural conduct" (see Figure 6-29).

Self-norm discrepancy: Self-rating was below the norm in "behavioural conduct", although only by a small amount (see Figure 6-29).

6.16.6 Communication domain

Self-others discrepancy: missing data

6.16.7 School/learning

Self-others discrepancy: Self-report was greater than teacher report in "scholastic competence" (see Figure 6-29)

Self-norm discrepancy: Self-report was below norm in "scholastic competence" (see Figure 6-29)

6.16.8 Dan summary

There was incomplete data in this case. Dan was unable to provide self-report at times and he was too young to complete the SDQ self-rating. There was no agreement between Dan's self-report and the report of others in any of the five domains. Although, at times, his self-report was at an age matched level, particularly in the social and behavioural domains. He equally had difficulty identifying deficits in the Cooking Task.

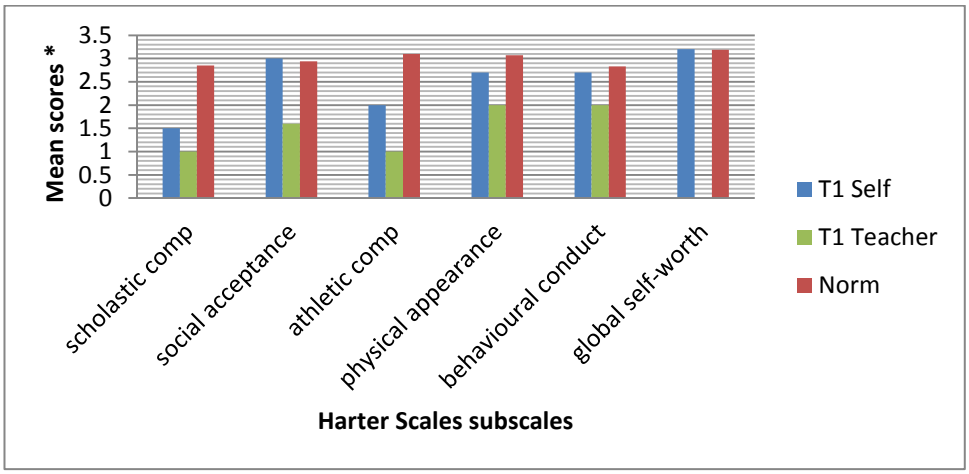

Figure 29: Dan - Harter Scales self-report scores compared to teacher report and normative values. *mean scores range 1-4

Table 6-38: Dan - SDQ parent ratings. *Descriptors – very low, low, close to average, high, very high

	Self-report	Parent report	Descriptor*
SDQ overall stress	Too young to complete self	25	Very high
Emotional distress		8	Very high
Behavioural difficulties		6	Very high
Hyperactivity and attentional difficulties		7	Slightly raised
Difficulties getting along with other children		4	High
Kind and helpful behaviour		4	Very low

Table 6-39: Dan - KIC parent ratings

Problems identified	Self-report	Parent report
Concentrating	Unable to complete T1	Yes
Getting tired easily		Yes
Remembering things		Yes
Keeping up with the rest of the class		No
Planning things, getting organized		Yes
Walking problems		Yes
Writing problems		No
Speaking or talking		Yes
Saying sentences so they make sense		No
Understanding what other people say		Yes
Reading		No
Feelings and behaviour		Yes
KIC Discrepancy Index (higher score = poorer awareness)		N/A

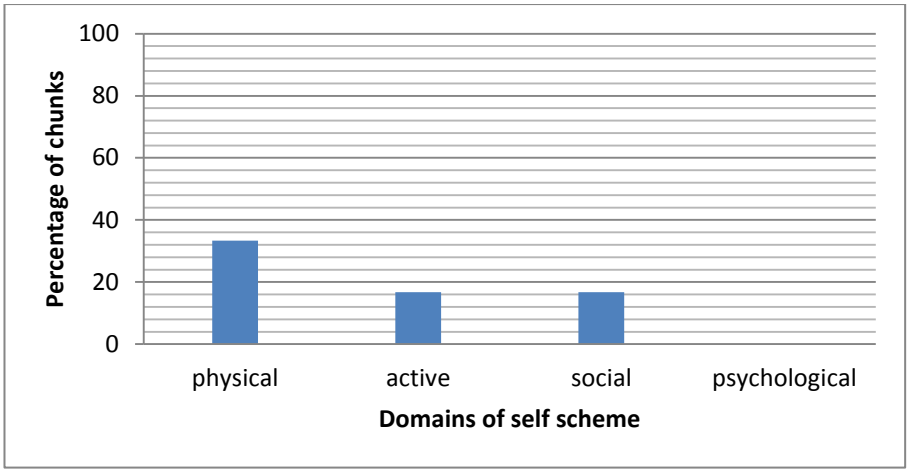

Figure 30: Dan - Percentage of SUI chunks coded to each domain at T1

Table 6-40: Dan - Cooking task scores

Cooking task	
Total error score	50
Goal achieved	No
Recipe located	No
Self-rating before	3
Self-rating after	6
Researcher rating	3
Discrepancy before-after	Yes
Discrepancy self-therapist	Yes
Do you think you'll have/you had any particular difficulties?	Before - not sure After -no

6.17 Visual data displays

In the following section each of the fifteen cases are summarised in a visual form. The visual data displays provide a quick overview of the results of each case for comparison purposes. The comparison will be used to inform the cross-case analysis that will be outlined in Chapter 7.

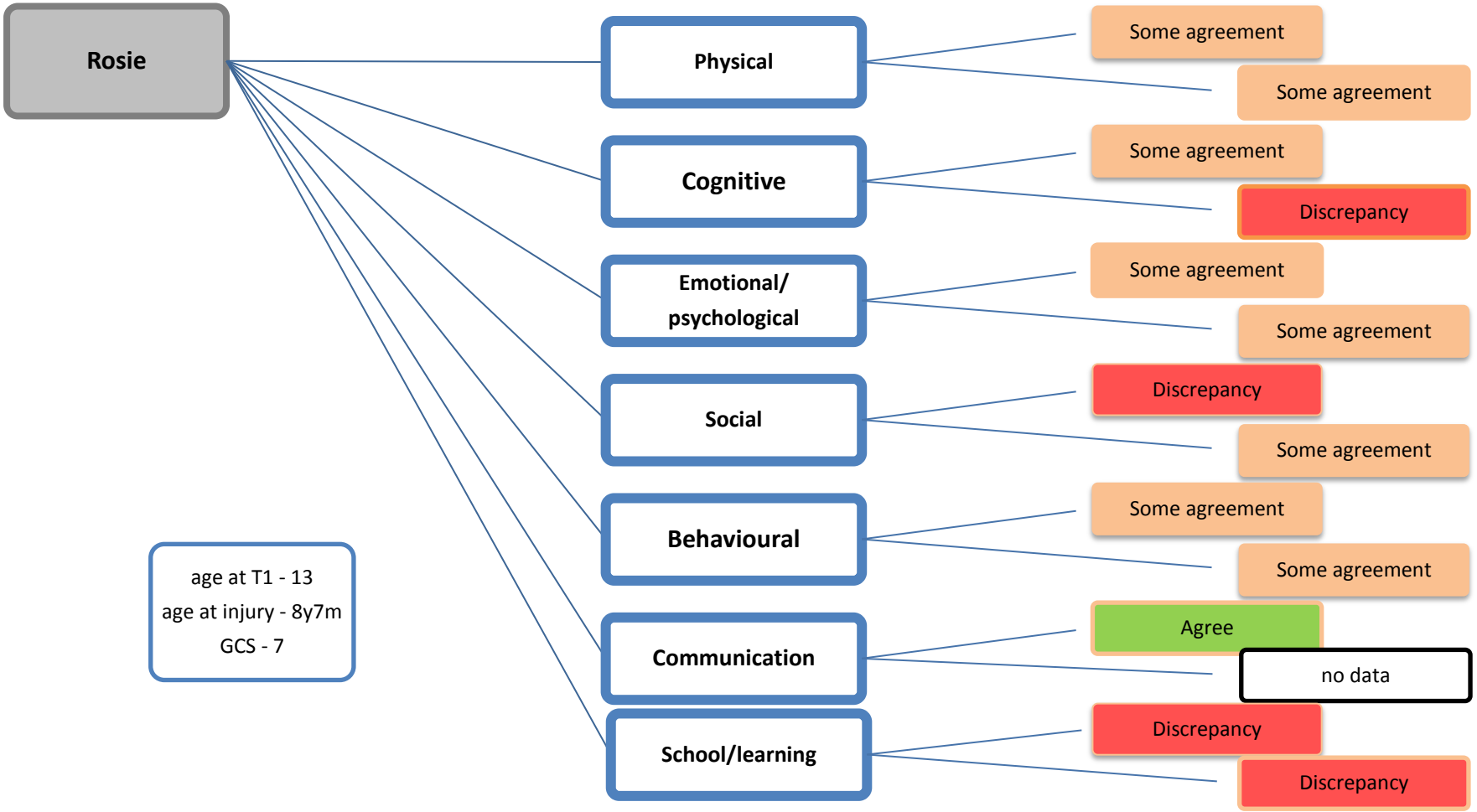

Figure 31: Rosie summary data display

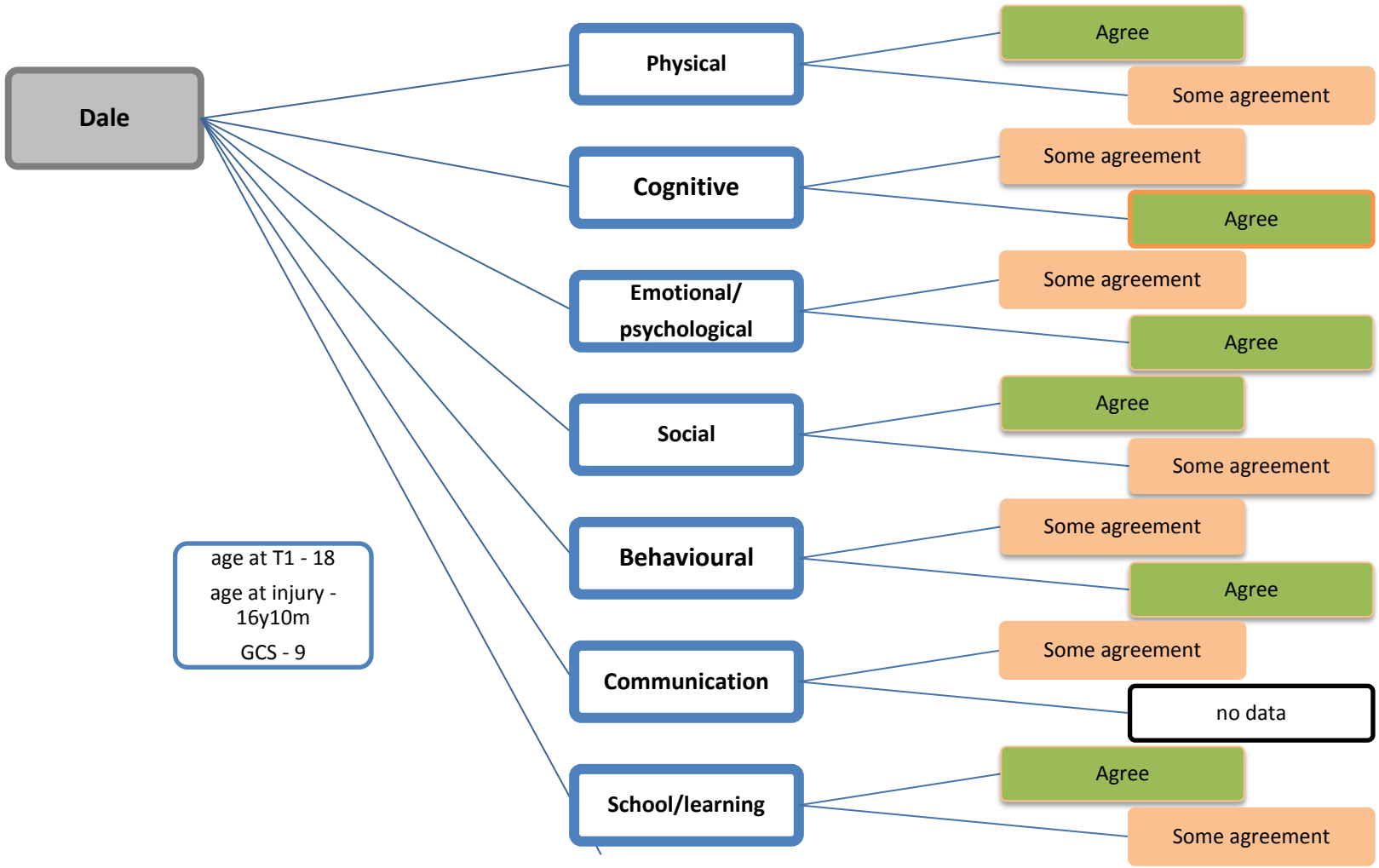

Figure 6-27: Dale summary data display

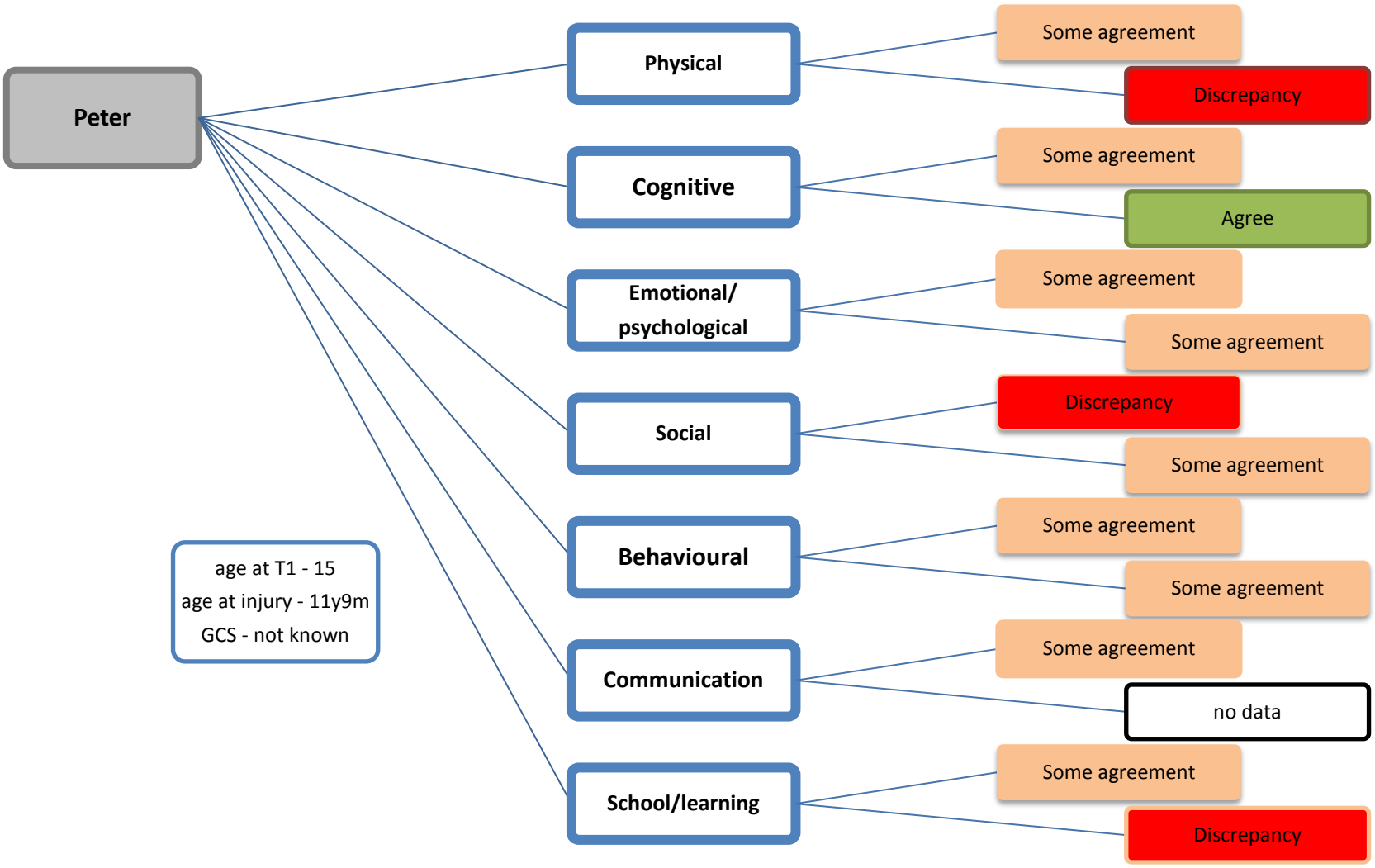

Figure 6-28: Peter summary data display

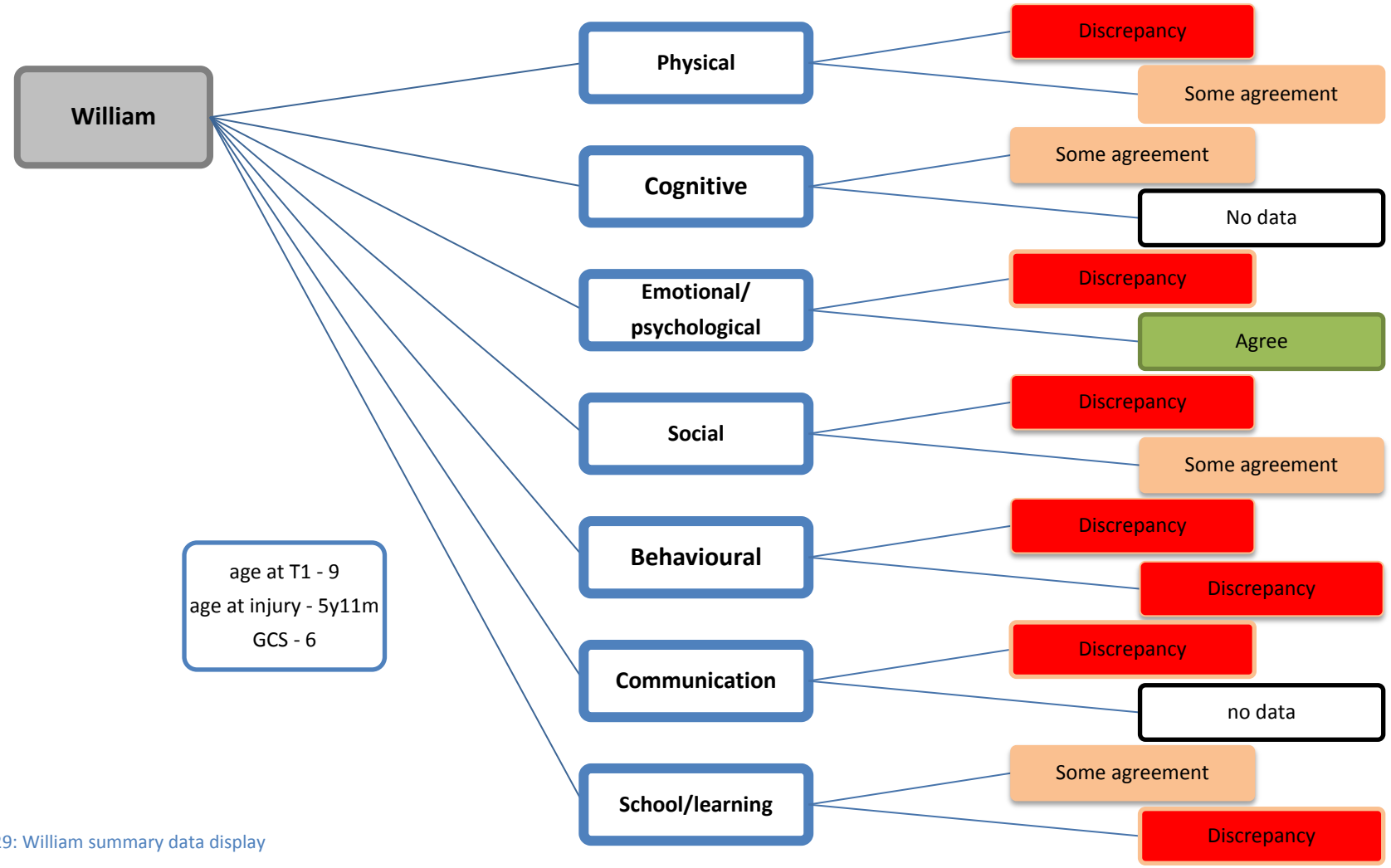

Figure 6-29: William summary data display

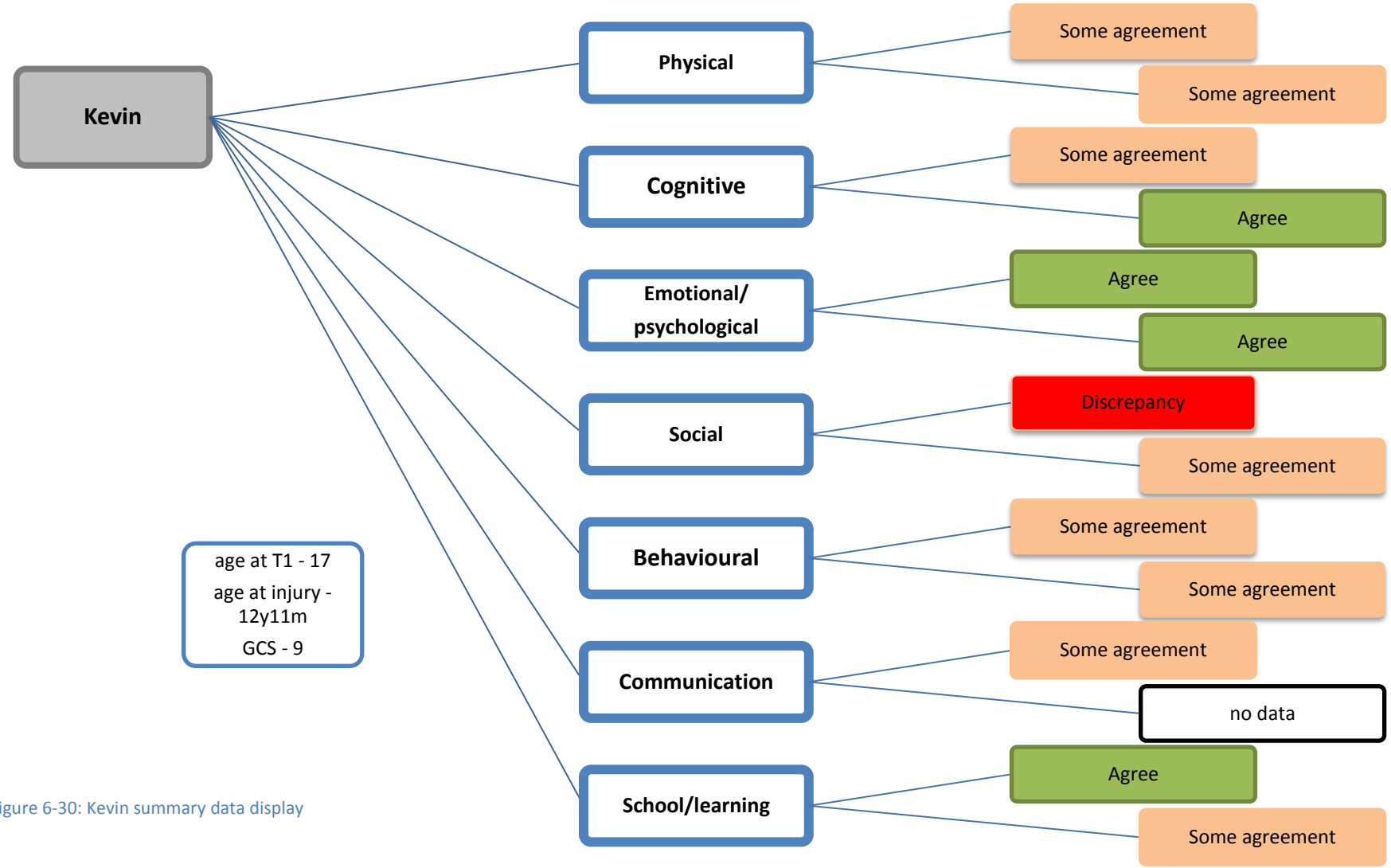

Figure 6-30: Kevin summary data display

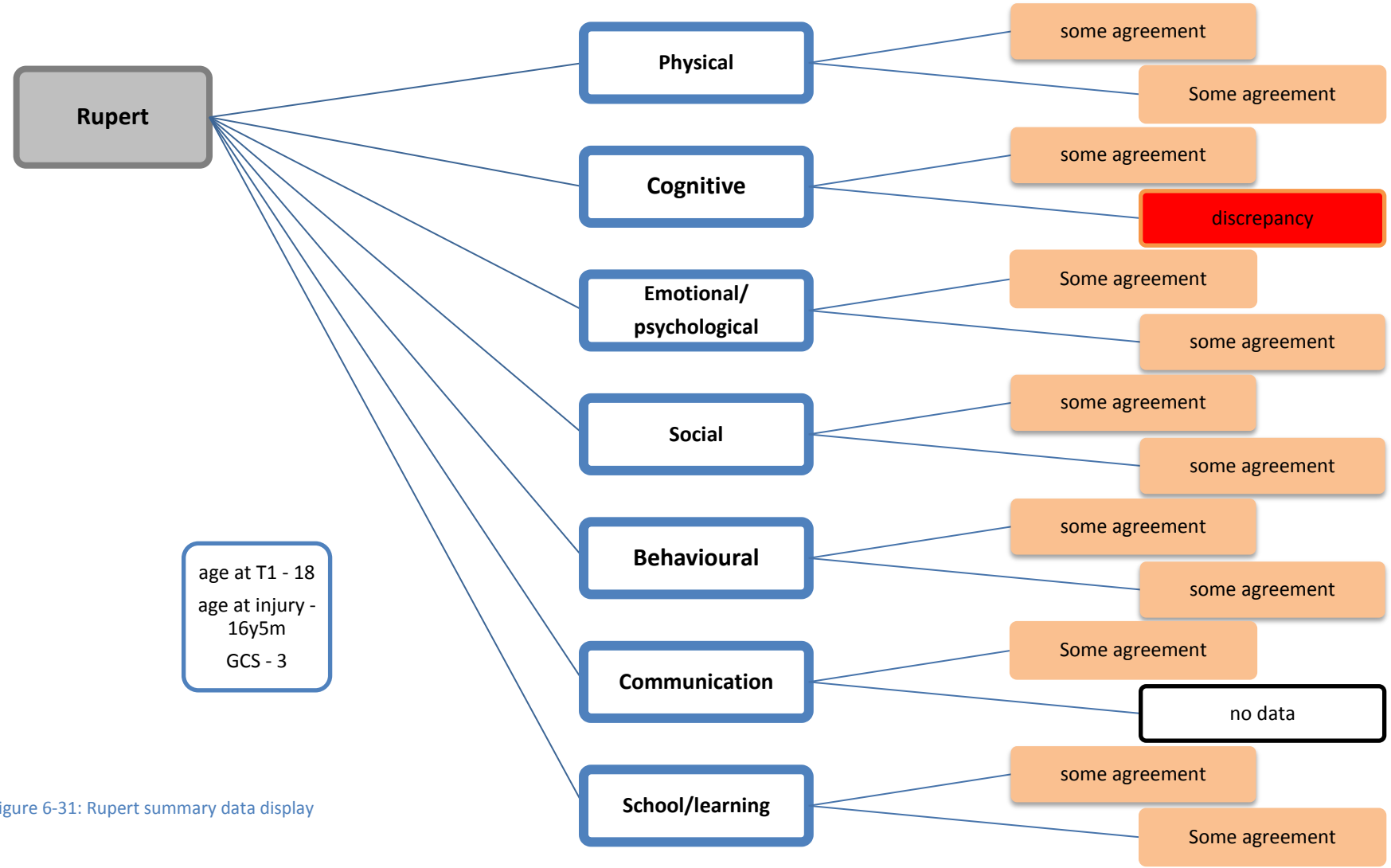

Figure 6-31: Rupert summary data display

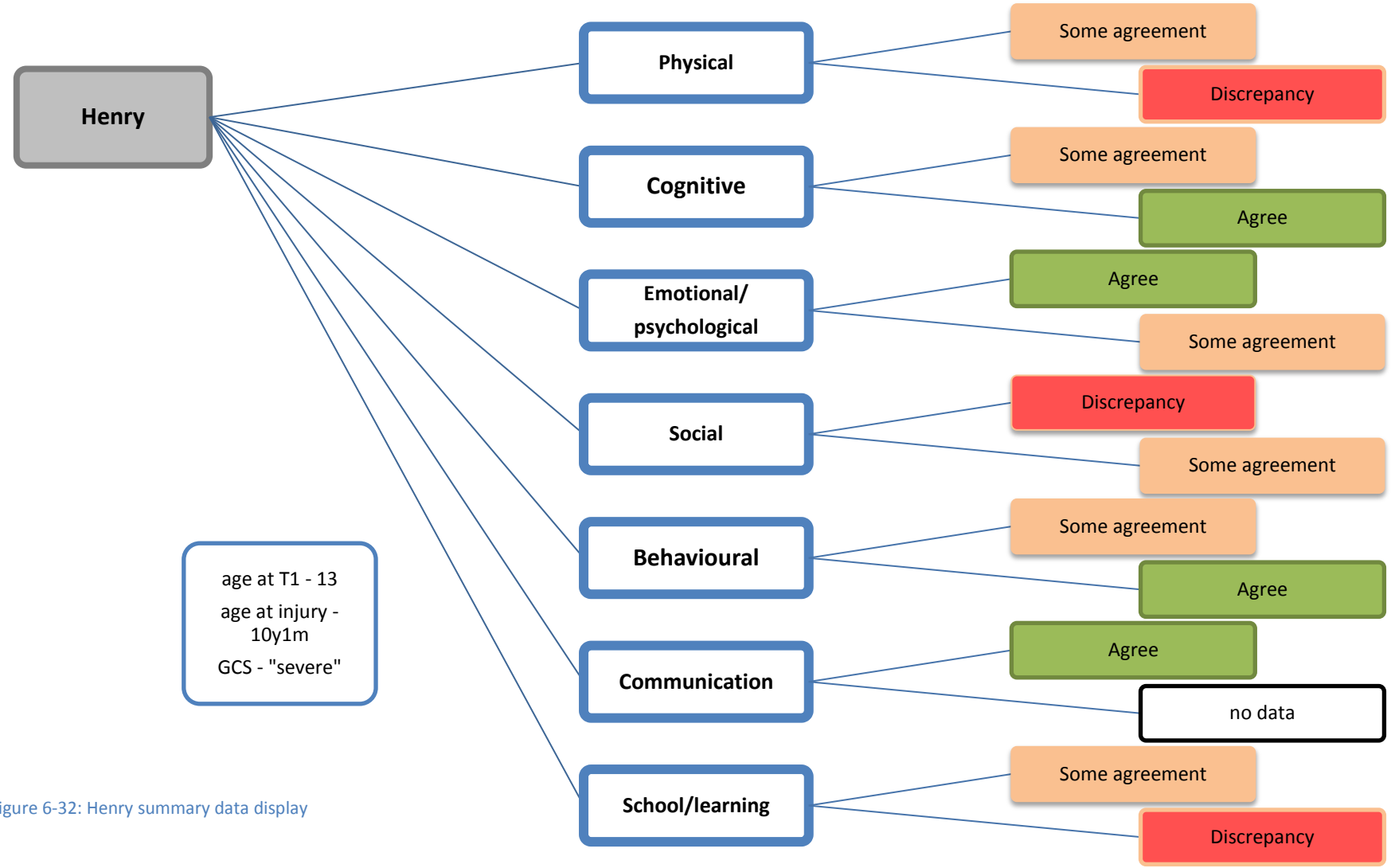

Figure 6-32: Henry summary data display

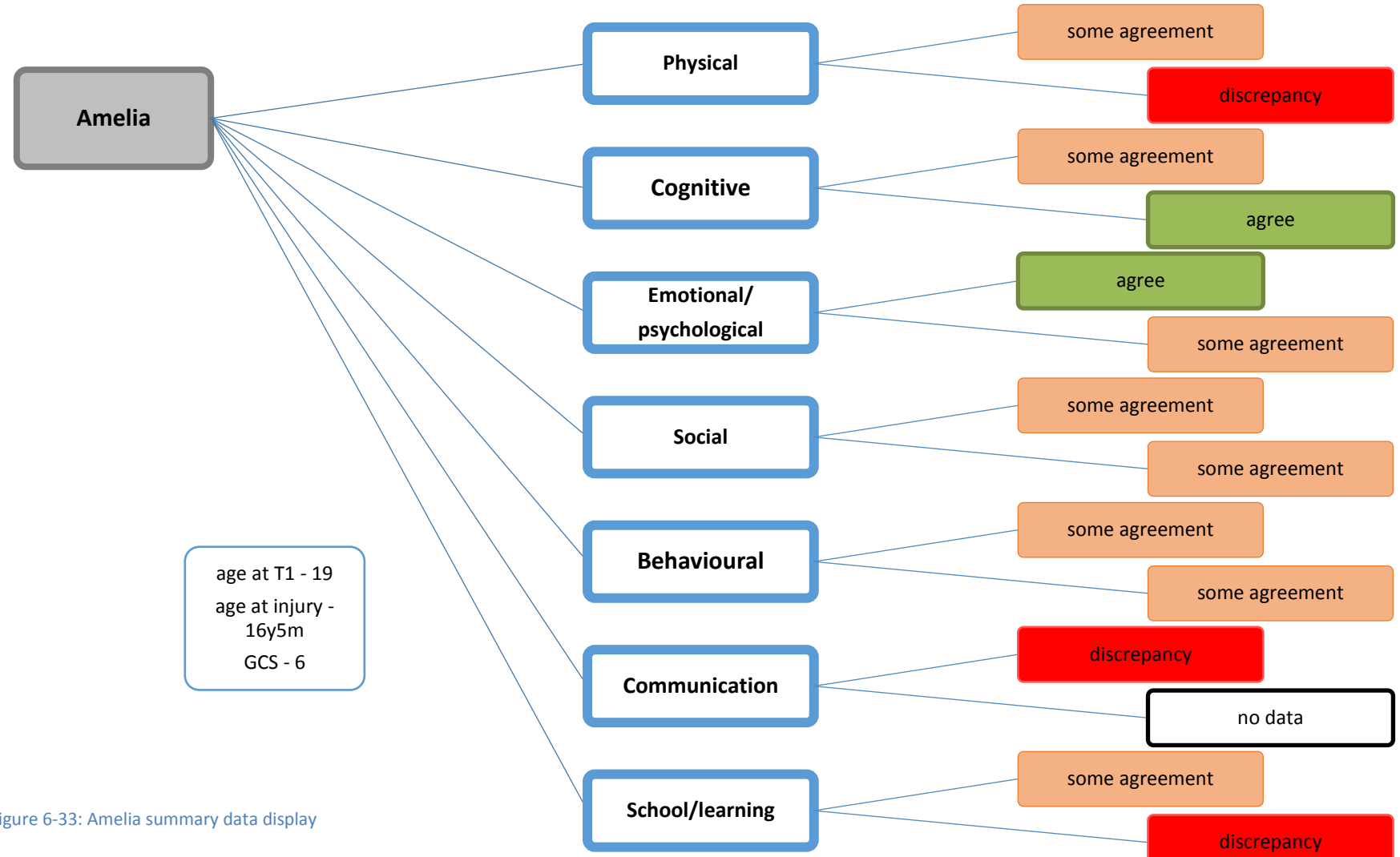

Figure 6-33: Amelia summary data display

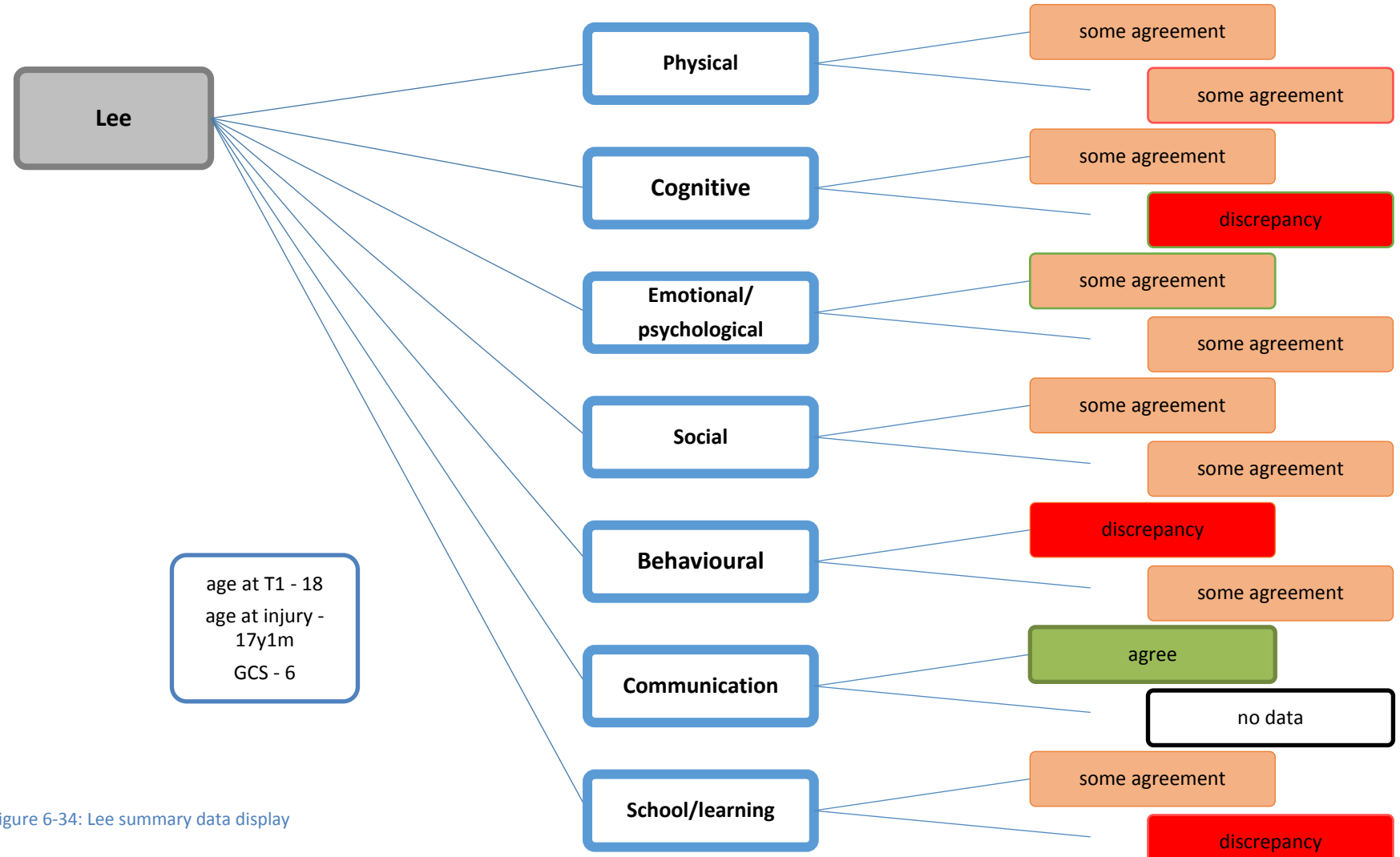

Figure 6-34: Lee summary data display

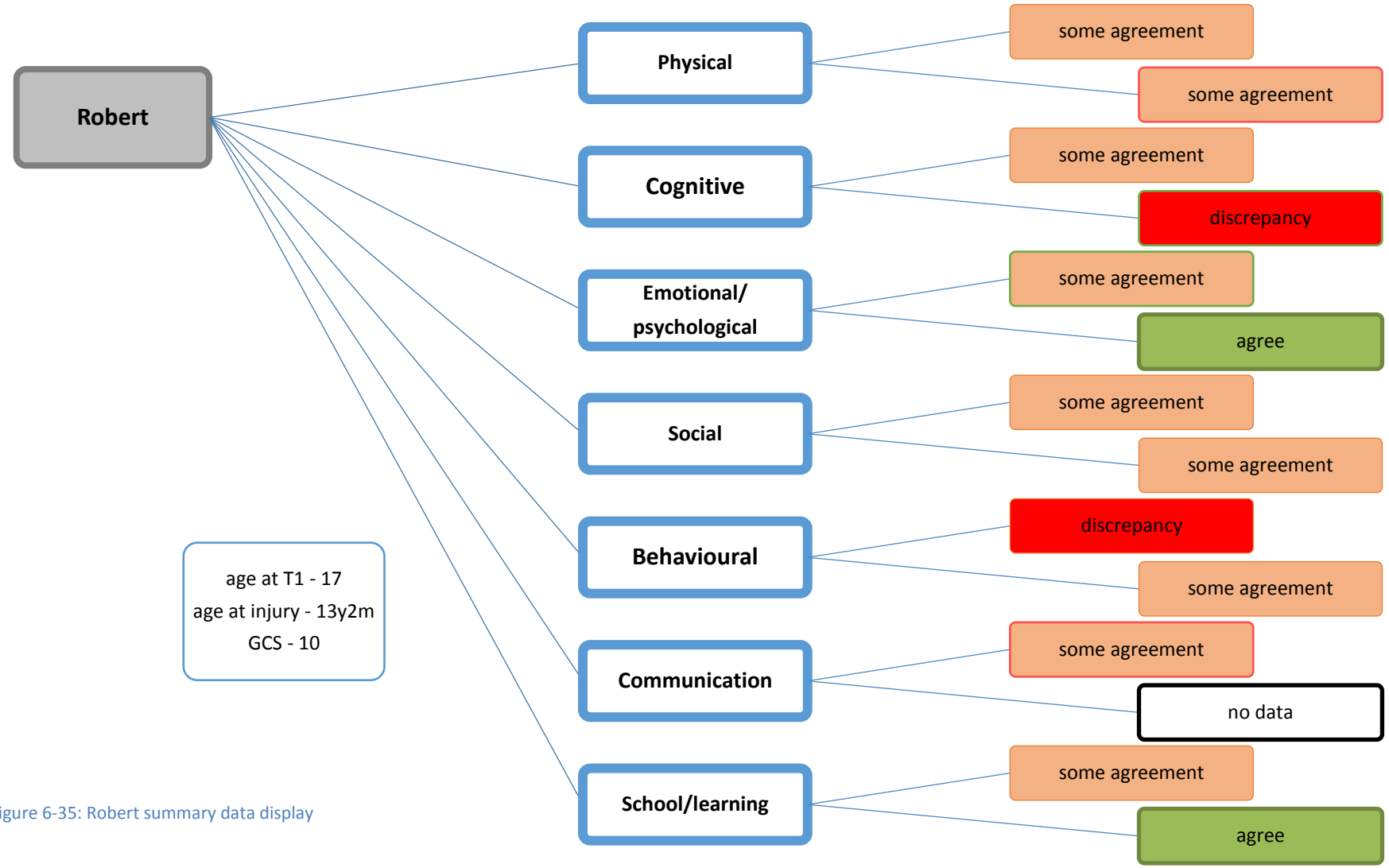

Figure 6-35: Robert summary data display

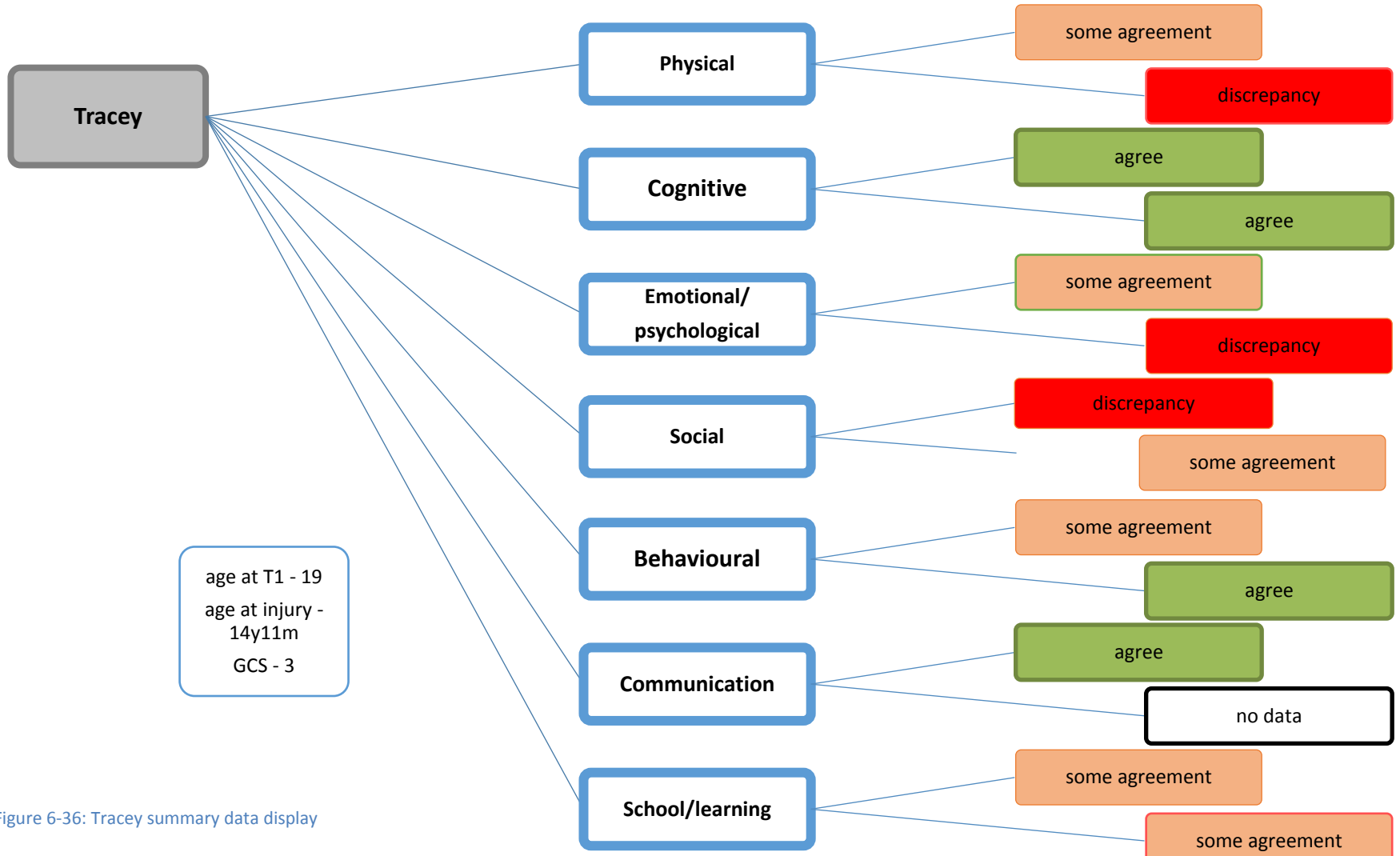

Figure 6-36: Tracey summary data display

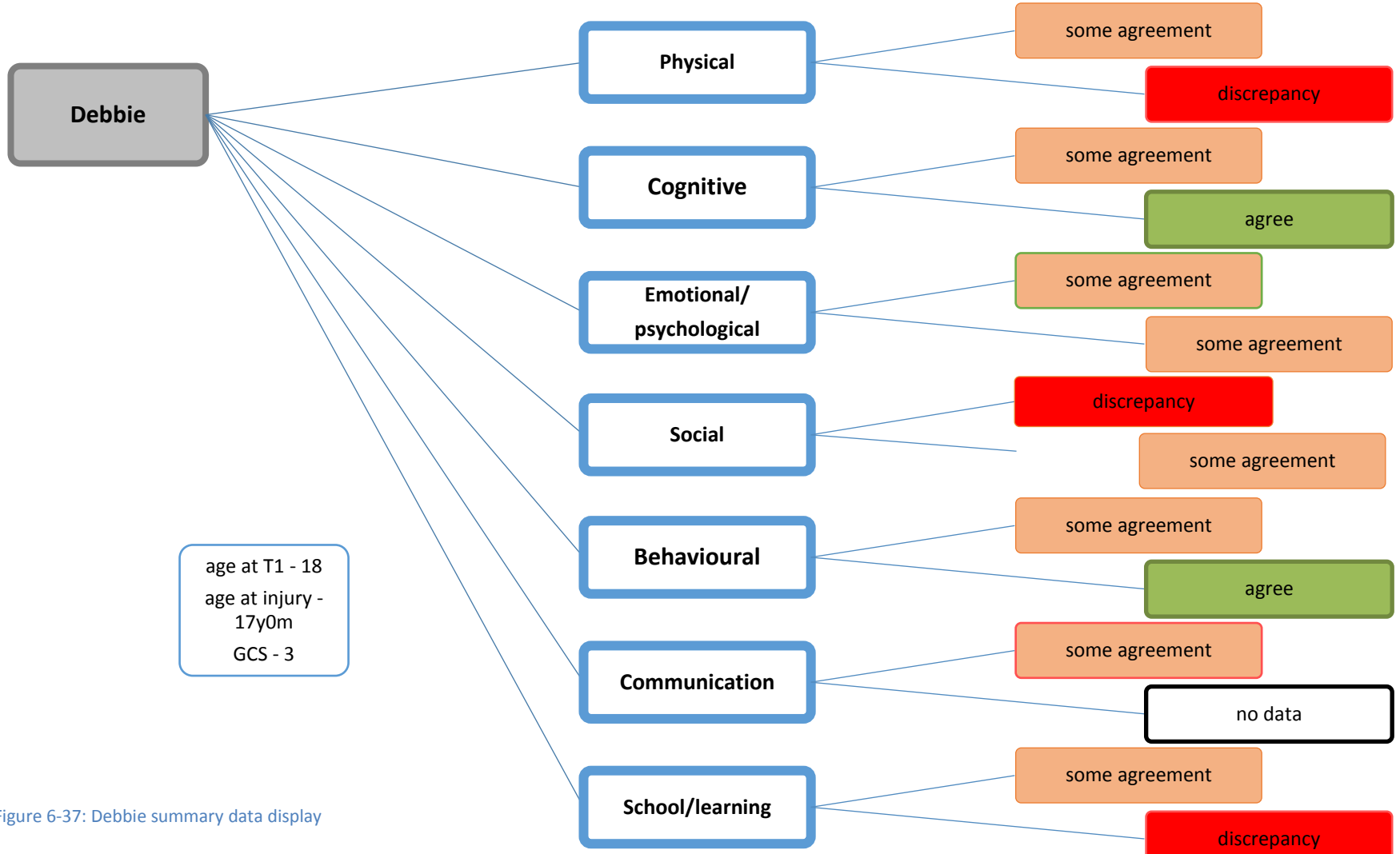

Figure 6-37: Debbie summary data display

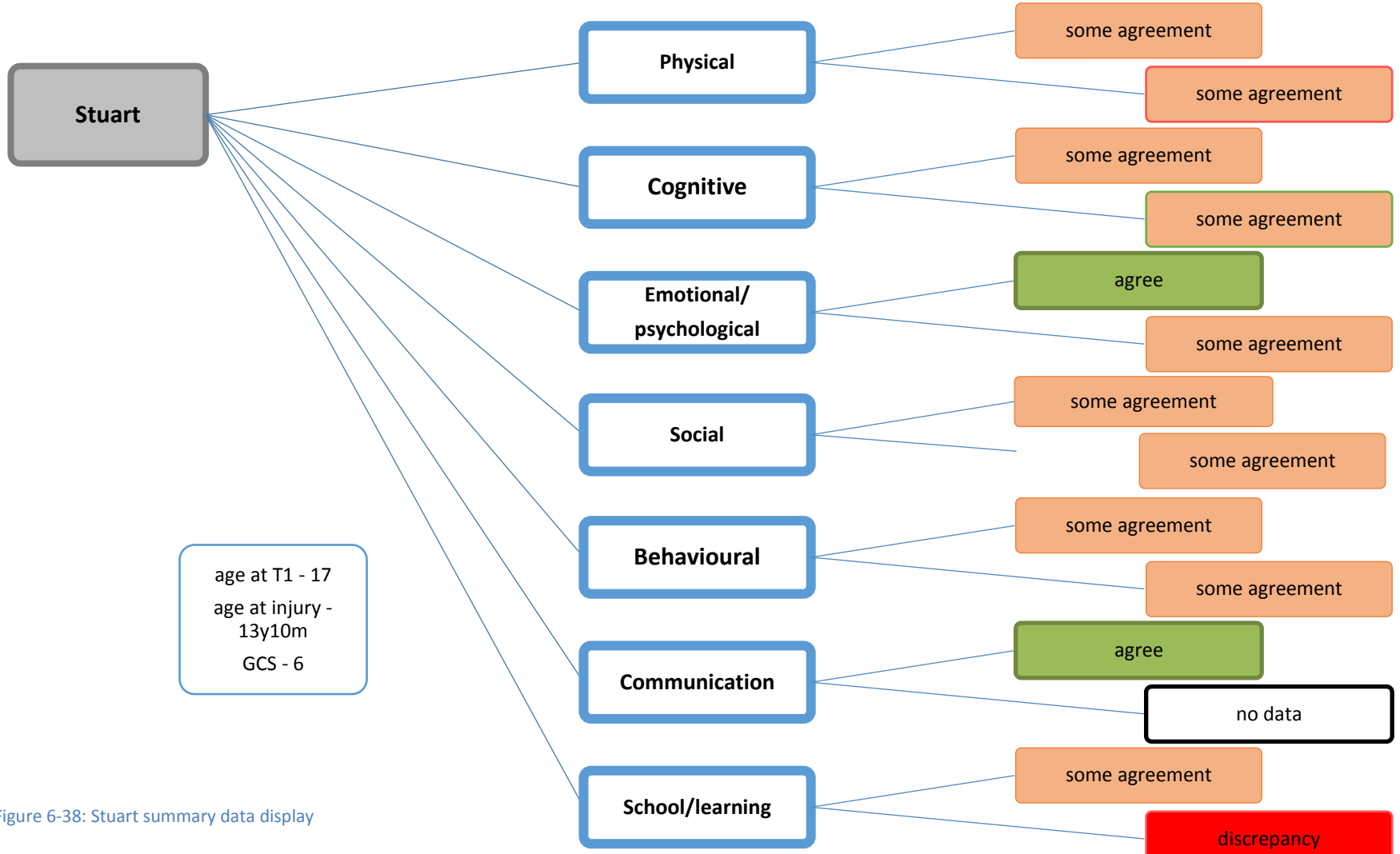

Figure 6-38: Stuart summary data display

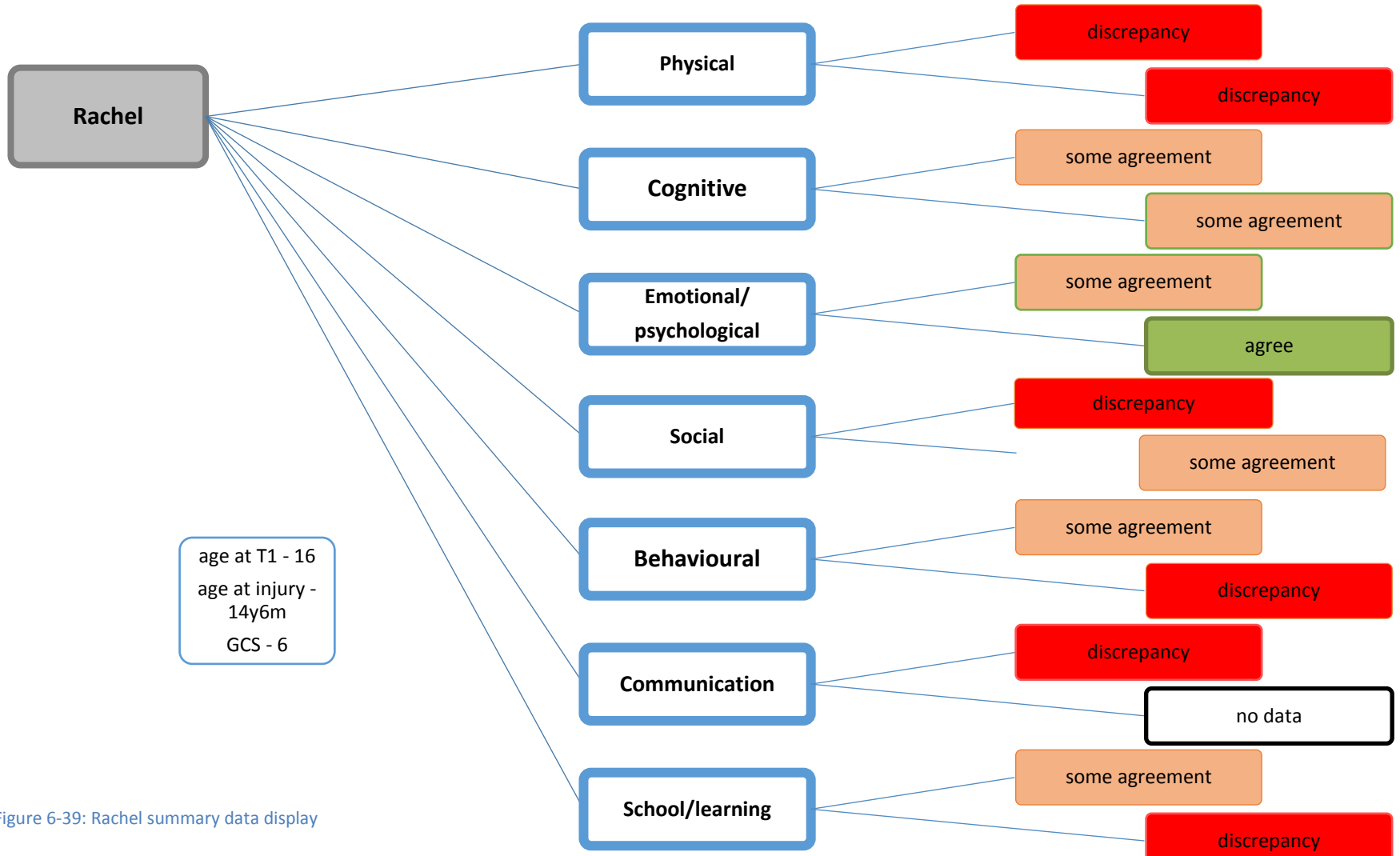

Figure 6-39: Rachel summary data display

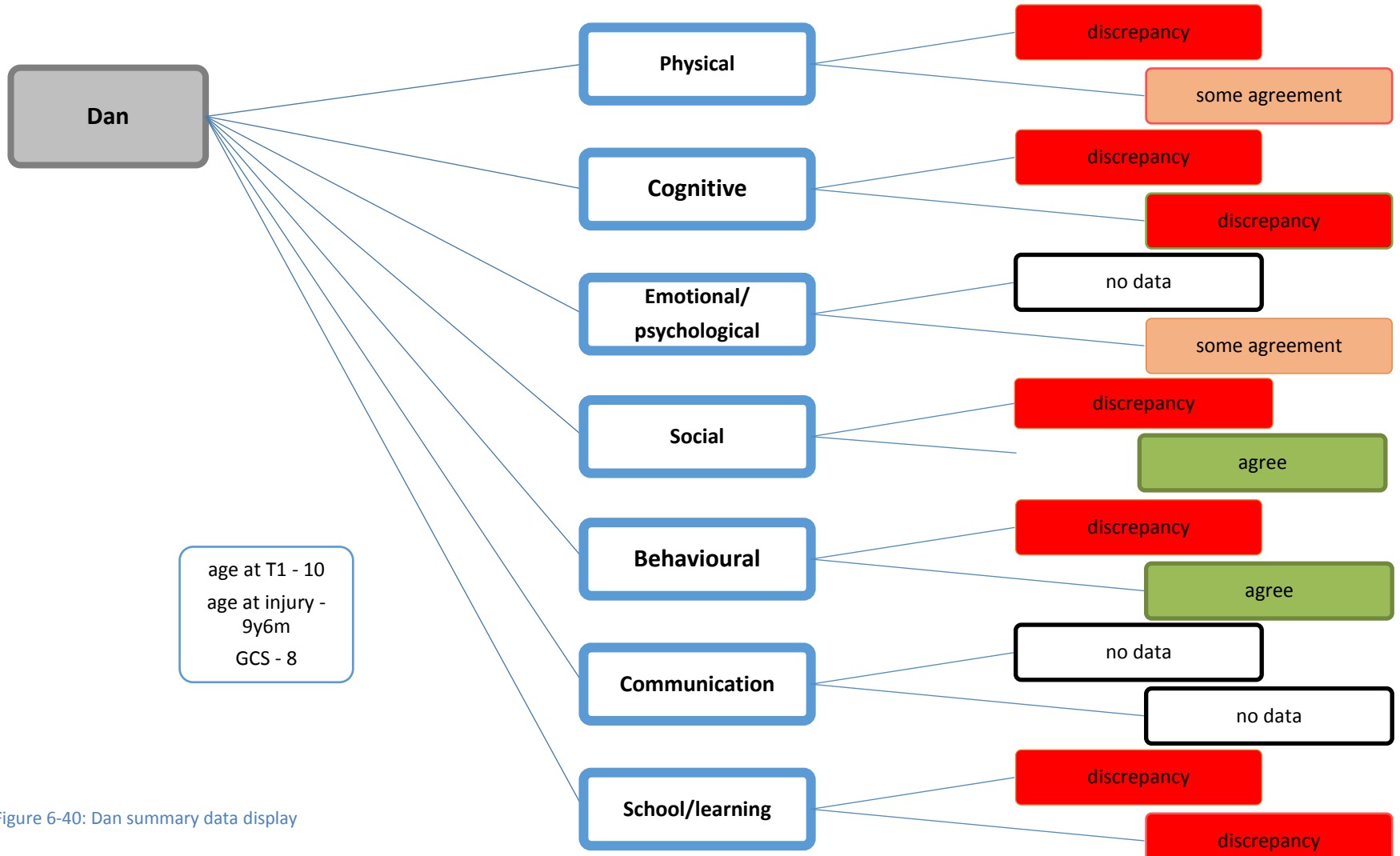

Figure 6-40: Dan summary data display

6.18 Summary

This chapter has presented the results from each of the fifteen individual cases in order to address the initial two research questions.

1. *Explore the profile of self-awareness following moderate to severe TBI in childhood*

The data for each of the fifteen cases have been presented across seven domains of function – physical, cognitive, emotional/psychological, social, behavioural, communication and school/learning. There were data from parents, teachers and researchers, to compare and so calculate the discrepancy. The data were sufficient to provide a profile of self-awareness in each of the cases. A visual representation was provided using a red/amber/green system for each child/young person. At a glance it was possible to learn the level of self-awareness for each case. All cases had some discrepancy in at least one domain of function.

2. *Compare the profile to typically developing children as reported in the literature*

In all but one domain (communication) there were normative data available and it was possible compare the data, and calculate a discrepancy from the norm. It was possible to add the self-norm discrepancy to the visual data displays, again using a red/amber/green system for each child/young person in each domain. All cases has some discrepancy from the norm in at least one domain of function.

The interview data is next to be presented. The methodology of the thematic structure and the thematic data from the fifteen children and young people will be presented in the next chapter in order to contribute further to the second research question.

7 Chapter 7 – Results of thematic analysis

7.1 Introduction

This chapter will include the results from the thematic analysis of the Self-Understanding Interview data. In Chapters 6 and 8 the scoring system for the SUI data was used and the data were presented in a quantitized form. The data was compared to normative data in Chapter 6 and the changes in the results over time were presented for each case in Chapter 8. In this chapter the text data has been subject to thematic analysis and first the development of the thematic structure will be explained and then the common themes from each case will be presented. The themes will be compared to normative trends.

7.2 Development of thematic structure

The Self-Understanding Interview (SUI) was administered at T1, T2 and T4. A total of 34 interviews were recorded, transcribed verbatim and assigned themes following the process of thematic analysis (Braun and Clarke, 2006, Miles and Huberman, 1994). The interviews were transcribed and read and re-read by the researcher until they were very familiar. The transcripts were imported into NVivo 10 software for analysis. Parts of the typed text were highlighted and an initial descriptive code was assigned. The initial themes emerged inductively through an iterative process. Initially descriptive codes were assigned to the T1 interviews and then the coding was reviewed. The initial thematic structure was lengthy and descriptive in nature (see Figure 7-1). The coding structure initially reflected the structure of the interview (ie self in past, present and future, physical and

psychological characteristics). It was not possible to use this initial coding structure to achieve reliable repeated coding. The researcher had difficulty accurately replicating the coding of interviews.

Independent coding was carried out by members of the PhD supervisory team. As expected there was a difference in the description of themes by the different members as a result of their different professional backgrounds (Miles and Huberman, 1994).

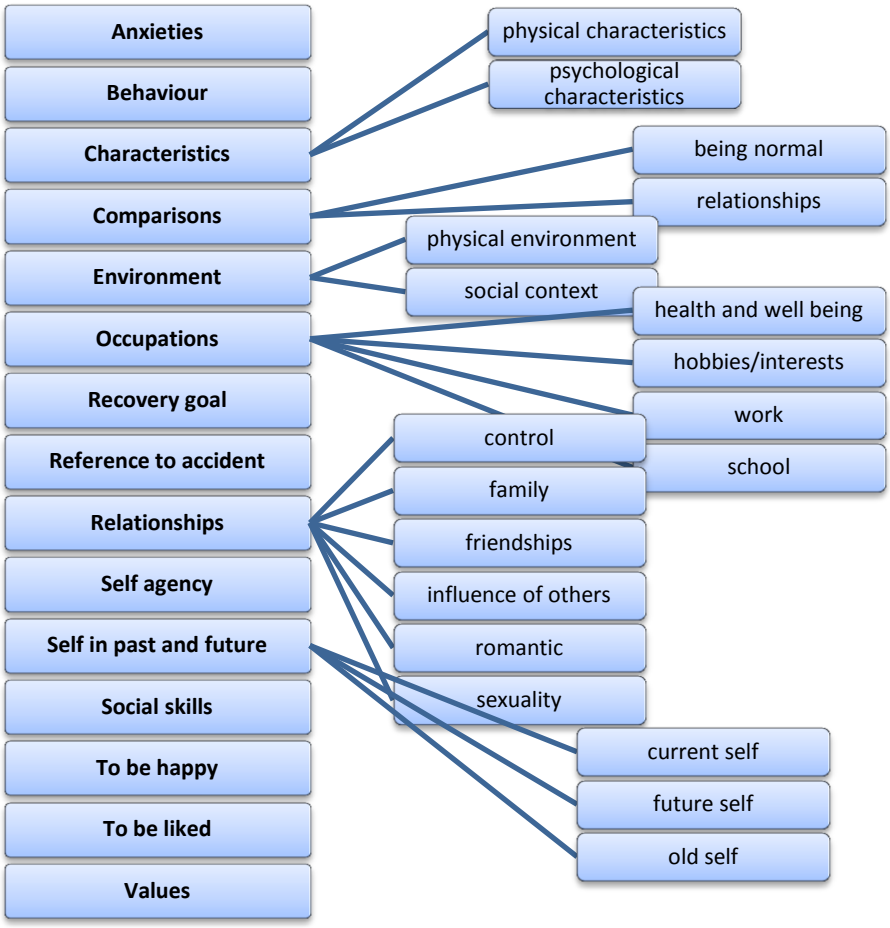

Figure 7-1: Coding structure following T1

The initial thematic structure was used to assign codes to the T2 interviews and further development of the thematic structure was iterated. The next version of the coding structure did not have new themes but the themes were reorganised and restructured to make sense of the interview data (see Figure 7-2). The number of primary themes was halved. Descriptions were outlined for the seven primary themes to aid consistent coding of the data (see Table 7-1).

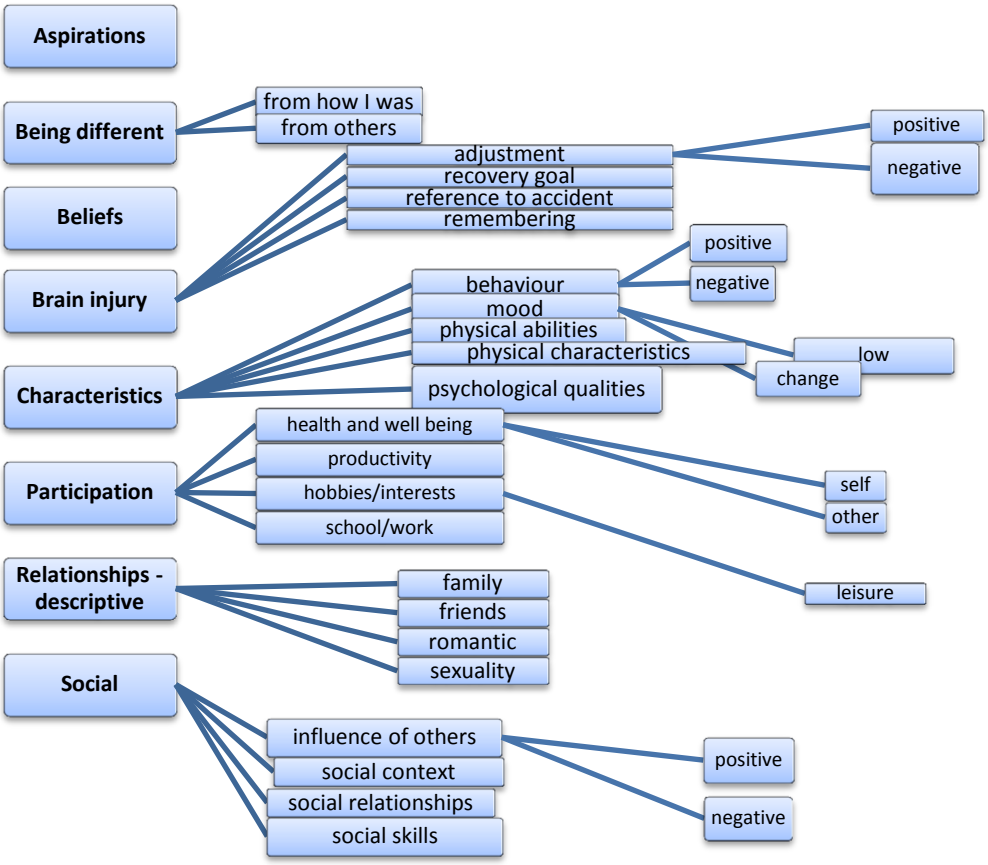

Figure 7-2: Revised coding structure at T2

Table 7-1: Supporting definitions for coding structure

Themes	Descriptions
Aspirations	To include recovery, rehabilitation as well as life plans and goals. Including material and physical as well as social
Being different	How see self in relation to others, being "normal" and also how see self as different from when younger or before accident
Beliefs	Attitudes and beliefs, how they feel about issues - what's important. Particular response to "what is good for you?" and "how did you get to be the way you are?"
Brain Injury	Narrative that relates to their brain injury including the injuries, the accident, consequences and how they have adjusted
Characteristics	Descriptive narrative about physical and psychological characteristics and abilities
Participation	Descriptions of what they do, how they spend their time including health and well being and productivity
Relationships - descriptive	Descriptions about the different types of relationships they have

While the structure was reorganised and subthemes matched to primary themes, the aspirations and beliefs of the children/young people were not grouped. The aspirations and beliefs were often very different to each other and the individual nature of the comments was retained to fit the case-study design.

The thematic structure was utilised at T4 to code the interview data. There was some residual conflict in the coding of social and relationship material. Social and relationship codes existed in a number of areas within the structure. The researcher consulted the ICF-CY (World Health Organisation, 2007) to clarify terms and definitions and the final coding structure was established (see Table 7-2 and Figure 7-3). "Socializing" was added as a subtheme of participation. A primary theme of "interpersonal interactions and relationships" was renamed for clarification and to make coding more consistent. The secondary theme of psychological qualities was changed to "psychosocial qualities" to capture the more descriptive data about social characteristics.

Table 7-2: Supporting definitions for final coding structure

Theme	Definition
Socializing	Engaging in informal or casual gatherings with others, such as visiting friends or relatives or meeting informally in public places
Interpersonal interactions and relationships	Carrying out the actions and tasks required for basic and complex interactions with people (strangers, friends, relatives, family members and lovers)
Psychosocial qualities	General mental functions, as they develop over the lifespan, required to understand and constructively integrate the mental functions that lead to the formation of the personal and interpersonal skills needed to establish reciprocal social interactions, in terms of both meaning and purpose

The final thematic structure had greater code-recode reliability. Cross-checking of coding reached 91% consistency for the research team. There were only 4/45 items coded differently between the two time points. Three items were as a result of different coding density in the two episodes. There was one more item with multiple coding at one time and two items with multiple coding at the other. The only item with a difference of coding between the two episodes was between the themes “belief.relationship” and “interpersonal interactions and relationships.friends”.

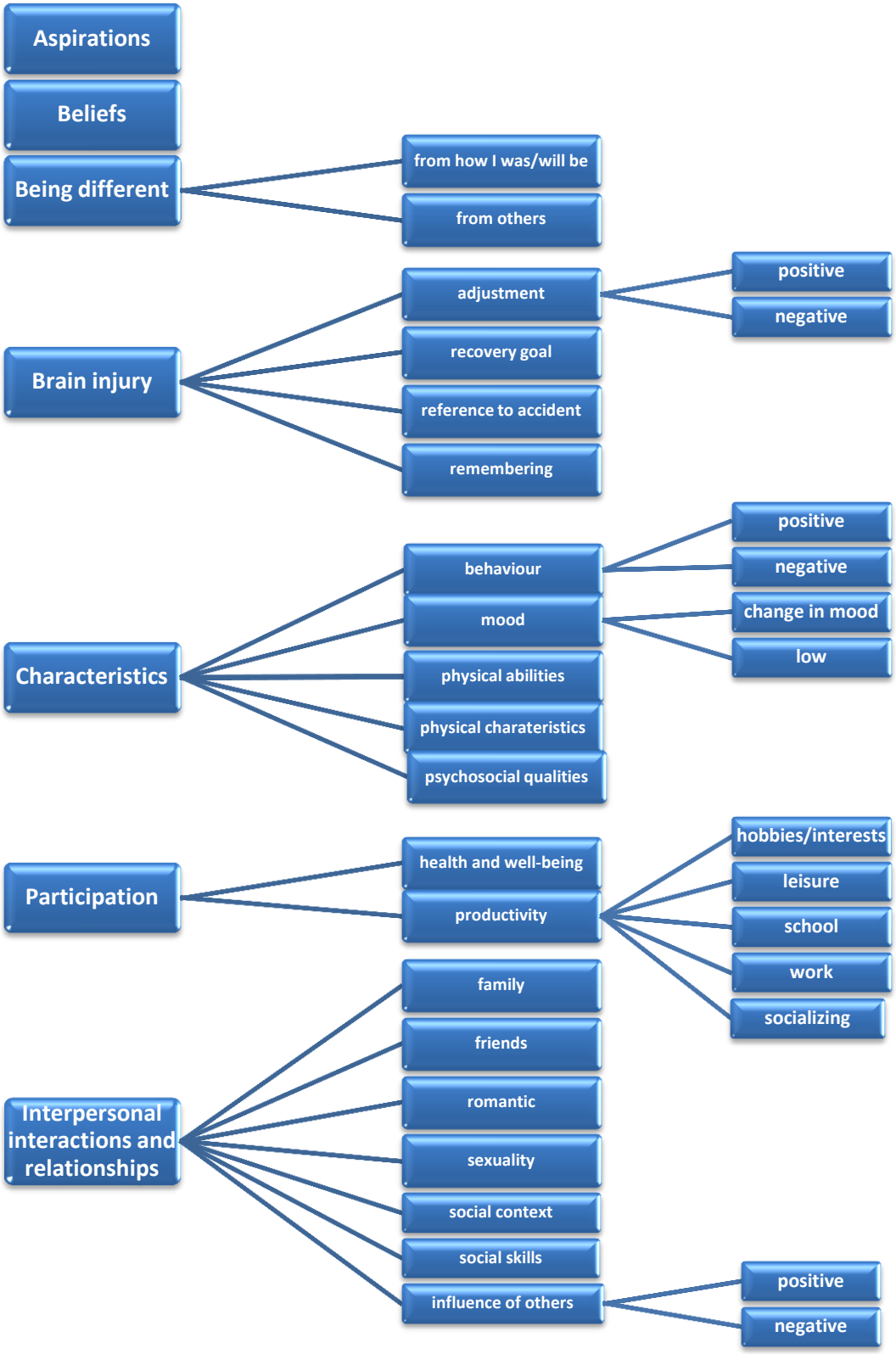

Figure 7-3: Final thematic structure of interview data

The primary themes were

Aspirations

I want to be an RSPCA officer (Rachel)

Maybe just make me happy (Amelia)

Beliefs

Well you get better jobs, earn a better salary, have a better life when you're older (Amelia)

Money makes the world go round (Lee)

Being different

I'm different from everybody and how I was (Amelia)

I'm older….I've got a brain injury …and everything is different now (Lee)

Brain injury

It's really hard to think about the future because of what happened to me (Amelia)

I'll still have a brain injury…the future will tell (Lee)

Characteristics

I'm a girl…I've got brown hair (Rachel)

A fun, bubbly little person (Henry)

Participation

I like coming home and having a nice bath (William)

If I don't have my medication erm I'm pretty much falling asleep in every psychology lesson (Stuart)

Interpersonal interactions and relationships

I've got true friends and I can trust my family and my friends (Debbie)

My brother will still annoy me (Amelia)

7.3 Individual themes of cases

Each of the cases had their own set of themes at T1. They will be described in the following section with individual quotes.

7.3.1 Rosie narrative themes (8 years 7 months at injury; 13 years at recruitment)

There was no clear theme that dominated in Rosie's interview. There were a number of themes with a similar percentage of data. The range between the six most common themes was only 9-15% (see Figure 7-4)

The most common theme was concerned with "being different". Firstly to how she currently was and secondly to how different she would be in the future. The structure of the interview prompted some of this content:

…like in year 7 I wasn't that like social and stuff I was like I wanted to only be friends with people in my form so I could be closer to them but like in year 8 I've gone out and I'm like friends with everyone like in the year like so yeah

I don't think I've grown that much but I think I do grow and I think like my habits change like when I was younger

I think that I'll be different because like when you age you become a different person

There was reference to friendships in these narratives and another common theme that would be expected at this age was that of social relationships:

Well like I had this conversation with my friend the other day and he said I'm a really like genuine person. I'm really nice and I don't say anything bad about people

I'm friendly

There was a frequently occurring theme in Rosie's interview of 'self-agency'. There were six references that included how she would/would not have control of how much she changed and what her future choices would be:

I'm going to try and keep like some of my hobbies

…so I'm going to try and like keep liking like drawing because drawing is like a good thing to do

…so I want to like keep my mind on that cos I want to have something to like a target to reach so that I always have something that I'm aiming for

Rosie only referred to her accident in response to the question in the interview relating back to when she was younger. She cannot remember the details of her accident:

That's when I was 8 and I don't really remember stuff from when I was 8 because like I was in hospital for like 5 months or something like that, I don't really know and so I don't really remember that much from when I was 8

Rosie demonstrated awareness of her changing self and the importance of social relationships. These are common themes in early adolescence. Little discrepancy was noted.

Well like I had this conversation with my friend the other day and he said I'm a really like genuine person. I'm really nice and I don't say anything bad about people (Rosie)

All in all, around people I know pretty well I'm awesome, at least I think my friends think I am. I'm usually cheerful when I'm with my friends, happy and excited to be doing things with them (early adolescence, Harter)

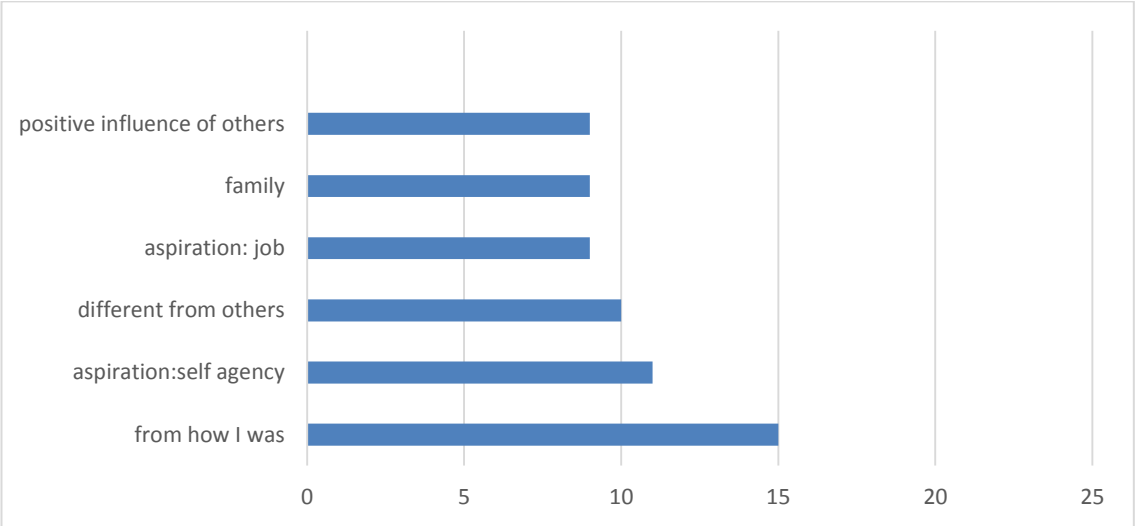

Figure 7-4: Rosie - common themes from SUI data

7.3.2 Dale narrative themes (16 years 10 months at injury; 18 years at recruitment)

Within the more common themes in the interviews, Dale was concerned with how different he felt from others as well as how different he was from how he used to be (see Figure 7-5). He mostly related these differences to physical aspects of himself and his appearance:

> *I didn't have long hair and that. I had a really bad dress sense.*
>
> *… think I'll be the same but by appearance I'll be different by the way I look*
>
> *What will be the same is my hair laugh and the way I dress. The only difference is I'll have my tattoos then and my ear will be bigger ok and that's it really*
>
> *one of the differences about me the reason I'm the same as most people cos I get we're the same people cos like I'm getting a full body tattoo up to my neck and I'm stretching my ear quite big as you can see and yeah that's it. I'm growing my hair but a lot of boys seem to grow their hair but they seem to be cutting it now*

However, at times there was an emergence of the more abstract elements of personality and experience that can change over time:

> *Well everyone changes from year to year like from experiences*

The other commonly occurring theme was social relationships:

> *Some people don't like me as I am but some people do*

…sometimes you have to relate to that person and what their needs are and adapt

I'm always the person someone comes to to help them out and talk to. I talk about things. My guy friends come to me to talk about personal things like the girls they come to me cos no other guy will understand. Relationship counsellor

Dale only made reference to his accident once and it was in a comical manner. He responded to the question "How could you become different?" with "Another blow to the head!"

There was a discrepancy between Dale's themes and those in typical development. Although he had a common theme of social relationships that is common to adolescence, much of the content of his interview was more like that of a younger adolescent who is occupied with attributes that influence social appeal.

one of the differences about me the reason I'm the same as most people cos I get we're the same people cos like I'm getting a full body tattoo up to my neck and I'm stretching my ear quite big as you can see and yeah that's it. I'm growing my hair but a lot of boys seem to grow their hair but they seem to be cutting it now (Dale)

How I look and how popular I am are more important (Harter, middle to late childhood)

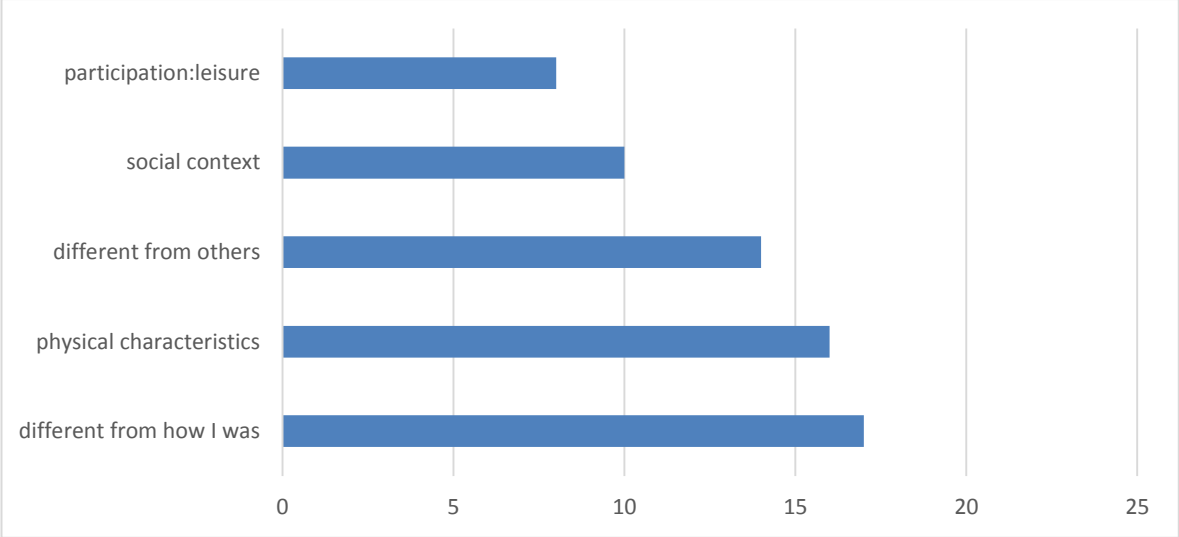

Figure 7-5: Dale - common themes from SUI data

7.3.3 Peter narrative themes (11 years 9 months at injury; 15 years at recruitment)

Peter had a commonly occurring theme of how different he was from how he had been (see Figure 7-6). He spoke of the past in both a generic and a specific manner:

Nothings the same, everything's different

When talking specifically he included some of the more physical aspects – growing and learning to talk. Furthermore, in response to questions about the future he spoke of how you could change in the future and that others could support you:

…they could talk to you, you ideas like how to change

This dialogue was also related to the theme of positive influence of others and how they could help you to change.

Peter spoke of his physical characteristics a few times but in a brief and concrete manner

Grow taller

My appearance changes

My face

My body grows bigger

Another theme was self agency and how Peter could be the agent of future change:

I'll get to choose what to do

Then I can choose my own life and what I want to be

…I choose myself

The word "choose" is stressed here through the repetition.

Peter's interview does not have the longer more elaborate answers to be expected at his age:

I get angry quick

I'm a talented person

You're probably not going to understand. I'm complicated! With my really *close* friends, I am very tolerant. I mean I'm understanding and caring. With a *group* of friends, I'm rowdier. I'm also usually friendly and cheerful but I can get pretty obnoxious and intolerant if I don't like how they're acting.

(Harter, middle adolescence)

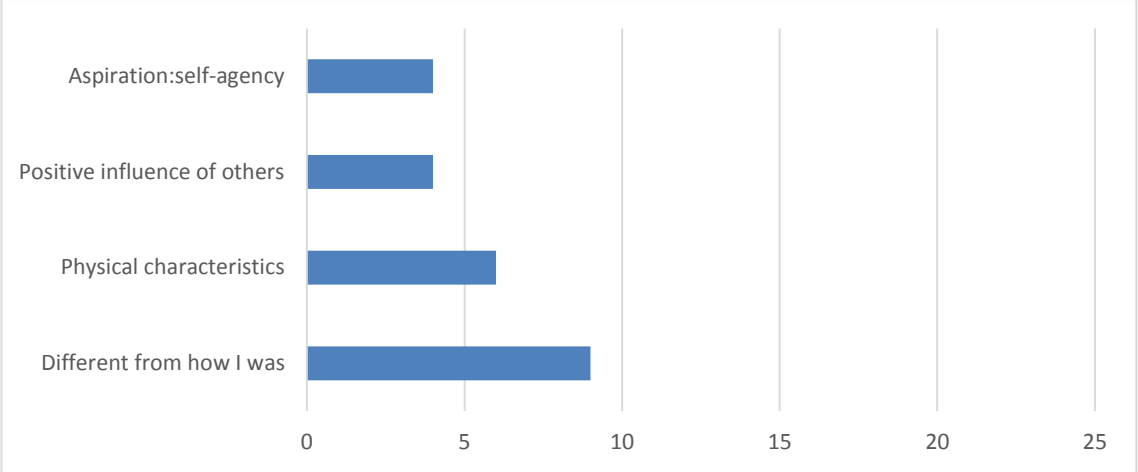

Figure 7-6: Peter - common themes from SUI data

7.3.4 William narrative themes (5 years 11 months at injury; 9 years at recruitment)

The four main themes from William's narrative were (see Figure 7-7):

Physical characteristics

I grow. Like a giant beanstalk

Aspirations: material wealth

What would you like to be? If you had three wishes what would they be?

Rock star, millionaire, get a monster truck

but I wish I could be a millionaire

Hobbies/interests: leisure

I like coming home and having a nice bath and tea and eating stuff and going to sleep with teddy and.... (starts to name all soft toys)

Health and well-being (T1)

What do you want to be like?

Fit and healthy …So I can do more things

I won't have a wheelchair any more …I'll be fit because I'm fat now and I'll be more enjoyable

At times the content of the interviews was very repetitive. At T1 William described himself as a pupil and then referred to the eye. References to the eye were then evident throughout the SUI and KIC:

I'm a pupil – the eye…

Do you know about the brain, what it does, what it controls?

Eyebrows – does the brain control them? Don't know. Bit of string attached to the eye….brain breathes and eye blinks (KIC)

Do you know if people have difficulties after an accident when they have hit their head?

Problems with their eyes…problems with their blinking (KIC)On some occasions Williams's narrative contained some very elaborate overestimations of his physical abilities more closely aligned to a younger child:

So I can do more things like tight rope and rock climbing (Mum: adventurous!) *and jumping on the trampoline so I can go through the clouds* (Mum: wow!) *and I'd fall back through…….*

I can run fast, and I can climb high, a lot higher than I could when I was little and I can run faster, too (Harter, early to middle childhood).

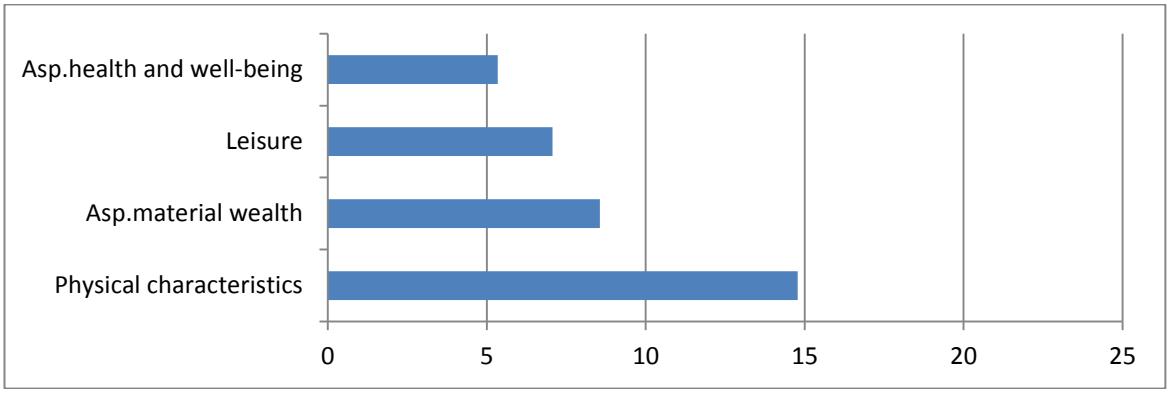

Figure 7-7: William - common themes from SUI data

7.3.5 Kevin narrative themes (12 years 11 months at injury; 17 years at recruitment)

Kevin's interview flowed easily and involved lengthy responses. The four most common themes from Kevin's data were (see Figure 7-8):

Being different from how I was/will be

I was unhappy like a few months ago eh about not having a job and I've gone out and I've got myself a job and so I'm quite pleased about getting myself a job

Interpersonal interactions and relationships – friends

I'm really confident and bubbly and if there's say a group of people who are feeling like quite down and bored and stuff, I'm like yeah let's go out, let's have a good time

I think that people enjoy my company,

Aspiration for self-agency

I just, this is, it's almost as though this was the high life for me ok and now I'm living it so I …I do things to keep myself on what I think will what will give me satisfaction… like personal like pleasures you know what I mean?

…the direction I want to take my life

Interpersonal interactions and relationships- sexuality

5 years ago I didn't really know what was going on in my head to be honest

Oh I was extremely different erm I think the biggest turning point in my life was when I came out as gay.

There was evidence of an emerging sense of integration of self with a focus on the future and evaluation of his strengths and weaknesses in relation to his future path that was typical of his age:

I'm quite happy with myself at the moment hmm I was unhappy like a few months ago eh about not having a job and I've gone out and I've got myself a job and so I'm quite pleased about getting myself a job

Basically, I like who I am, so I don't stay depressed for long

(Harter late adolescence)

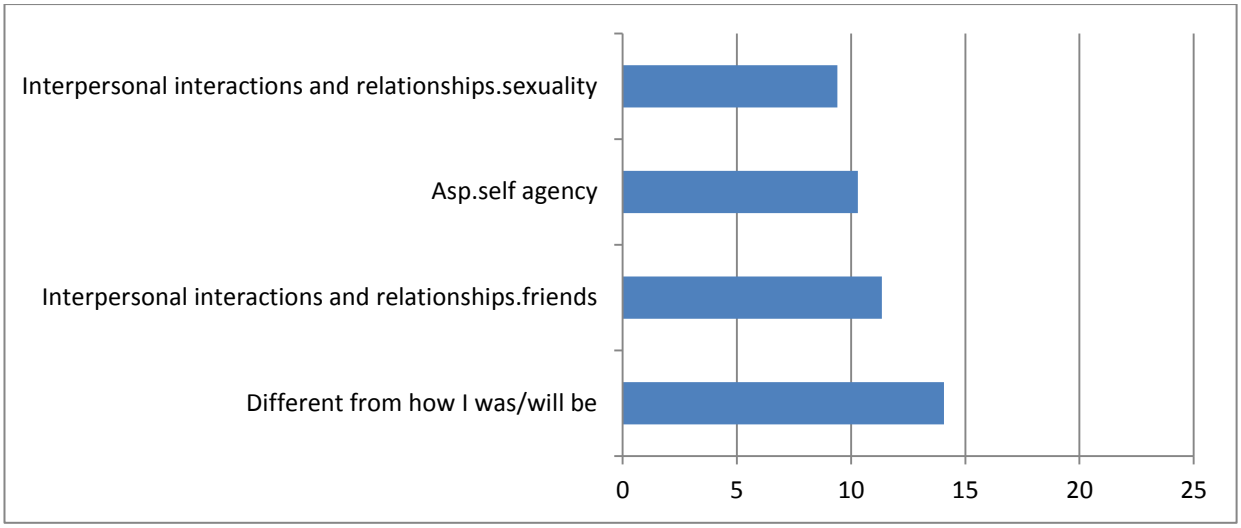

Figure 7-8: Kevin - common themes from SUI data

7.3.6 Rupert narrative themes (16 years 5 months at injury; 18 years at injury)

Rupert was tired during the interview and his answers were relatively brief. The four main themes were (see Figure 7-9):

Reference to accident (6.3%)

How did you get to be the way you are?

Cos of car accident

What difference did that make? *A lot of difference….in my head….and around my head*

Low mood (5.3%)

Cos if you are sad then you'll be lonely ok and depressed

I wouldn't have no friends and I'd be depressed

Interpersonal interactions and relationships - friends (5.3%)

I wouldn't have no friends and I'd be depressed

Physical abilities (4.8%)

What do you like least about yourself?

walking….Erm, I'm in a wheelchair….I want to walk

The interview transcript did not have the elaborate evaluative quality that would be expected at this age:

What sort of person are you?

A happy person

Why is it important to be a happy person?

Cos if you are sad then you'll be lonely ok and depressed

What difference would it make if you were like that?

I wouldn't have no friends and I'd be depressed (SUI, T1)

For example, I'd like to be an ethical person who treats other people fairly. That's the kind of lawyer I'd like to be, too. I don't always live up to that standard; that is, sometimes I do something that doesn't feel that ethical. When that happens, I get a little depressed because I don't like myself as a person. But I tell myself that it's natural to make mistakes, so I don't really question the fact that deep down inside, the real me is a moral person. Basically, I like who I am, so I don't stay depressed for long. Usually, I am pretty upbeat and optimistic. (Harter, late adolescence)

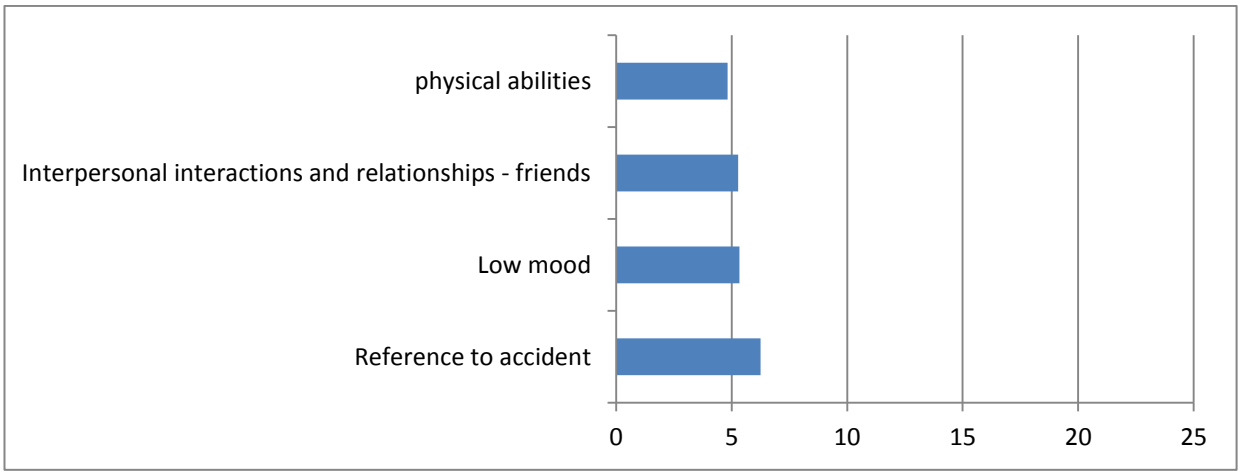

Figure 7-9: Rupert - common themes from SUI data

7.3.7 Henry narrative themes (10 years 1 month at injury; 13 years at recruitment)

Henry engaged with the interview and his main themes were (see Figure 7-10):

Being different from how I was /will be

> *…personality will be the same ok what I'm like will be the same, so if I'm sporty or not*
>
> What about, say 5 years ago, were you the same or were you different?
>
> *I was different*
>
> In what way were you different?
>
> *I used to talk more now I just grunt*

Interpersonal interactions and relationships – friends

*Cos I like having (*pause*) em verbal contact with other people (*pause*) and now it's all about the texting*

Beliefs – health and well-being

I'd probably be a fat lump sitting on the couch eating pizza

Ok and why would that be a bad thing?

No one would like you

Reference to accident

*All these scars …..It's just something on my body that I don't really want, want to be there (*pause*) Ok (*pause*)*

They gave me hope

Henry made reference to his physical appearance a number of times including the quote above. He spoke of the scar he had acquired since his accident and how girls may like him more if it was not there. He also said that he would not be liked if he was a couch potato. The focus on his physical appearance and how it affects popularity is more akin to that of a younger child:

How I look and how popular I am are more important. (Harter, middle to late childhood)

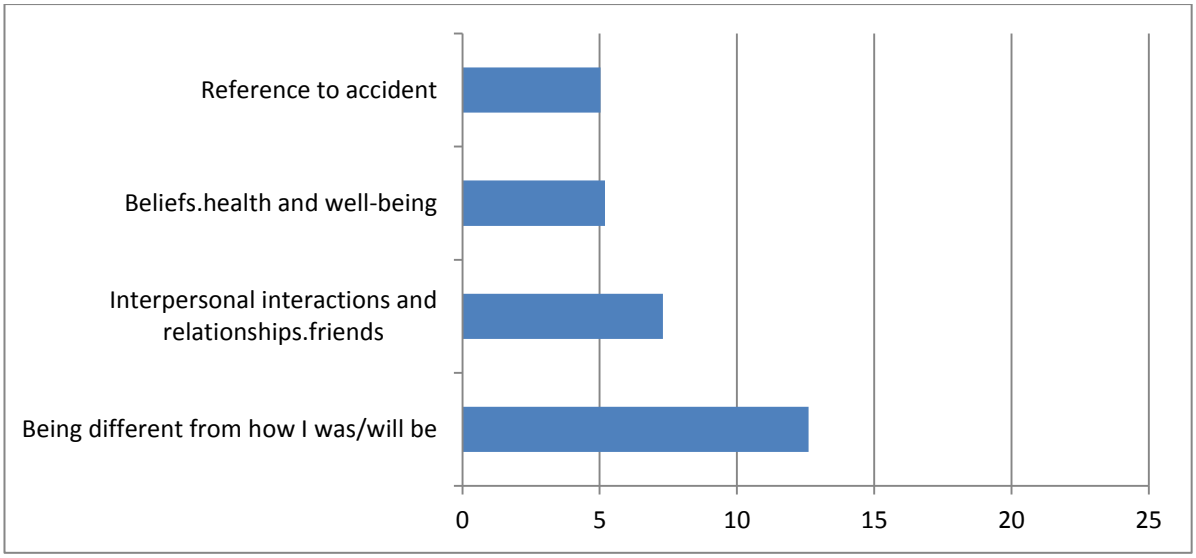

Figure 7-10: Henry - common themes from SUI data

7.3.8 Amelia narrative themes (16 years 5 months at injury; 19 years at recruitment)

Amelia's interview flowed easily and her most frequent themes at T1 were (see

Figure 7-11):

Reference to accident (7%)

> What are you especially proud of about yourself?
>
> *That I've managed to come out of the accident the way I have*
>
> *(*Reference to Mum*)Cos she's been through everything*

Physical characteristics (5.5%)

> (Reference to how you change) *I look the same….I haven't got taller in so*
>
> *long now…..I stay the same height*

Negative adjustment (5.4%)

Well it's been how many years now two thousand and.... it's been nearly 3 years now and if I can't get over it now, I doubt I'll ever be able to.....

Interpersonal interactions and relationships- family (4%)

Cos my Mum is also quite like determined…So that makes me determined..

Oh my brother will still annoy me

The quality of the narrative had an evaluative element which was similar to that of typical development

I don't like who I am as a person and I just can't get to grips with everything still.... what's happened to me and everything

And what difference does that make?

Well it's been how many years now two thousand and.... it's been nearly 3 years now and if I can't get over it now, I doubt I'll ever be able to.....

I'm pretty much being the kind of person I want to be. I'm doing well at things that are important to me like getting good grades. That's what is probably *most* important to me right now (Harter, late adolescence).

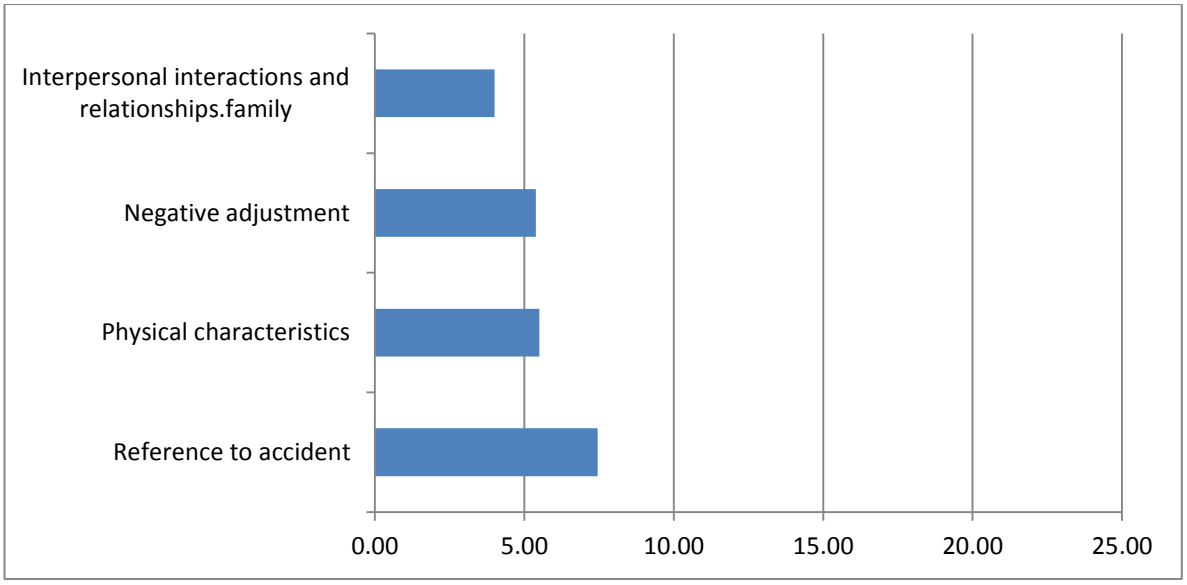

Figure 7-11: Amelia - common themes from SUI data

7.3.9 Lee narrative themes (17 years 1 month at injury; 18 years at recruitment)

Lee was very tired during the interview and his answers were relatively brief. The four most common themes at T1 were (see Figure 7-12):

Reference to accident (7.1%)

> What do you like least about yourself?
>
> *Having my accident*
>
> What will you be like in 5 years time?
>
> *I'll still have my brain injury …time will tell*

Aspiration - to be normal (6.9%)

> *I'll be more like normal compared to other people and that*
>
> What would you like to be?
>
> *Normal….a normal person*

Being different from others (6.2%)

There's only one me

They don't have the same surname as me

Beliefs – health and well-being (6.0%)

What do you think is good for you?

Oxygen…keeping us alive

His responses, as previously mentioned were rather brief. He also lacked the elaborate forward planning that would be expected at this age.

The future will tell…..the future will tell

Hopefully I'll be more like normal compared to other people and that (Lee, T1)

I'm a pretty conscientious person, particularly when it comes to doing things like my homework. It's important to me because I plan to go to college next year. Eventually I want to go to law school, so developing good study habits and getting top grades are both essential. (late adolescence, Harter)

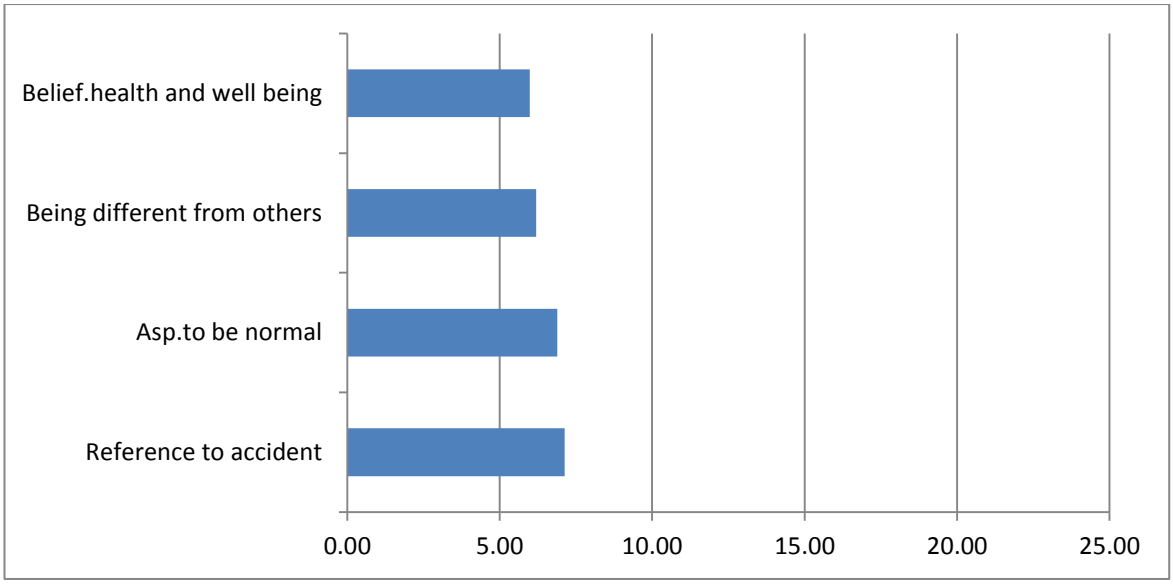

Figure 7-12: Lee - common themes from SUI data

7.3.10 Robert narrative themes (13 years 2 months at injury; 17 years at recruitment)

Robert's interview was brief at T1 and there was not sufficient data to analyse thematically (see Figure 7-13). Robert has severe communication difficulties and he chose not to use his communication aid. Instead he preferred to have his mother translate his speech for him. Two themes emerged:

Aspiration – to be the same. When asked what would be the same in 5 years he shared that he wanted to be the same and to still be bubbly. He endorsed that it was important.

Reference to accident. Robert reported that the accident was the reason that he was the person he was.

There was no reflection of the range of self abilities and how they integrate into the complex young person's self-narrative in Robert's interview. There was no elaborate future planning that would have been expected at this age.

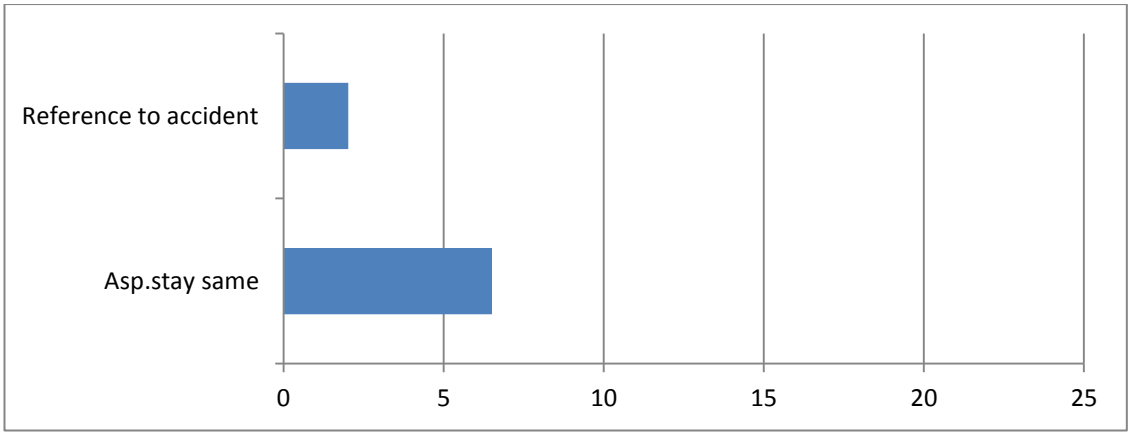

Figure 7-13: Robert - common themes from SUI data

7.3.11 Tracey narrative themes (14 years 11 months at injury; 19 years at recruitment)

Tracey's interview flowed easily and the four most common themes were (see Figure 7-14):

Psychosocial qualities (12%)

> What are you like?
>
> *Sociable, er I'm a bit of a perfectionist…bit of an OCD person*
>
> *I know that my brain is what controls my personality and that it will be the same even if I do take on different opinions; it will always be me because it's my brain.*

Beliefs – change (10%)

> *Cos everyone changes don't they? Mmm It's impossible to stay the same. Well, like, the people and everything, the environment around you, that changes as you change*

Being different from how I was/will be (9.7%)

> *if I'd like pushed myself I'd probably be happier with how I'd be like then I'd be happier with the position I'd have been in compared to the position I am in now*

Beliefs – relationships (7.6%)

> *It's important to be sociable because it gives you, it makes you like happier and it gives you like it makes your lifestyle better*
>
> *cos it's not a nice type of person to be and you're not really like if you're arrogant and rude.*

There is similarity between the typical pen portrait for late adolescence and this extract from the interview:

> What do you like least about yourself?
>
> *Um (*pause) *that I think I could have like pushed myself a bit more, to recover a bit more. I'm a bit lazy laugh*
>
> What difference does that make?
>
> *Pause em Then I'd be, if I'd, if I'd like pushed myself I'd probably be happier with how I'd be like then I'd be happier with the position I'd have been in compared to the position I am in now (Tracey T1)*

Every now and then I get a little lackadaisical and don't complete an assignment as thoroughly or thoughtfully as I could, particularly if our high school has a big football or basketball game that I want to go to with my friends. But that's normal, I mean, you can't just be a total grind. You'd be pretty boring if you were (late adolescence, Harter)

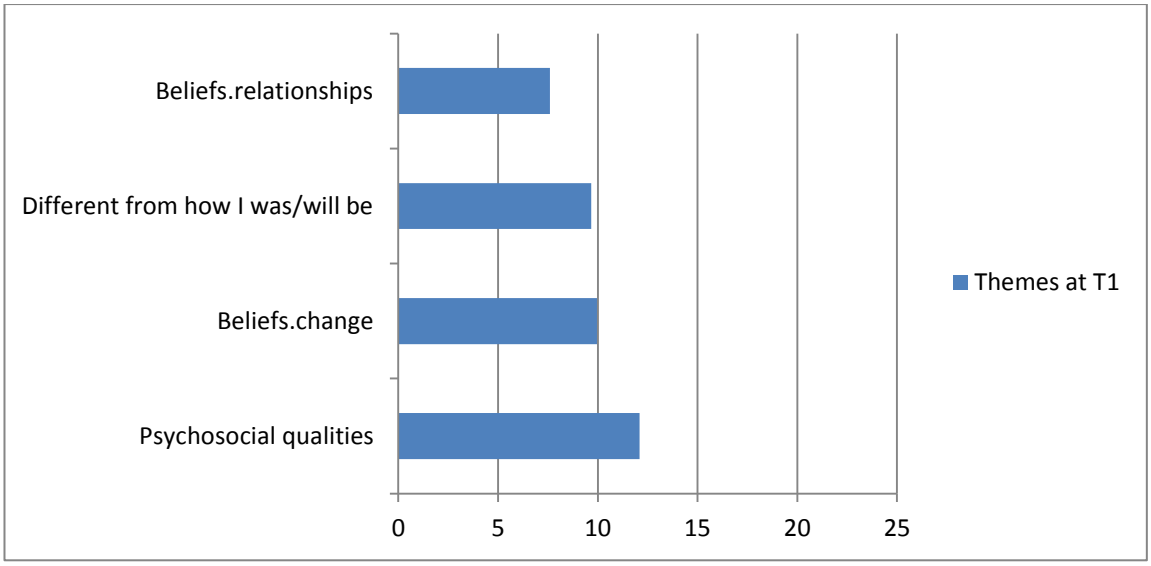

Figure 7-14: Tracey - common themes from SUI data

7.3.12 Debbie narrative themes (17 years at injury;18 years at recruitment)

Debbie's interview lacked flow at times and regular prompting and elaboration of questions was required. At T1 the four main themes were (see Figure 7-15):

Interpersonal interactions and relationships - friends (21%)

I've got friends I can trust … I've got true friends and I can trust my family and my friends

I made friends up at the Trust

Being different from how I was/will be (13%)

…well like you're obviously going to change when you're older but I don't know really I hope I am the same and they don't know a different me

I'm the same person as I was before

Reference to accident (13%)

What are you especially proud of about yourself?

Um that I've done what I've done and that I've moved on from getting run over yeah and now I'm just the same again

I would never regret getting run over right cos I've met some great people

Interpersonal interactions and relationships – family (10.5%)

Cos I wouldn't be here if my Mum and Dad weren't here

If it wasn't for my Mum and Dad I might be a horrible person

Debbie was able to elaborate in a manner typical of her age with the additional support of the prompts.

> *Um well like you're obviously going to change when you're older but I don't know really I hope I am the same and they don't know a different me (Debbie T1)*

> Having a lot of friends isn't that important to me. I wouldn't say I was unpopular, though. While I am basically an introvert, especially on a date when I get pretty self-conscious, in the right social situation, like watching a ball game with my friends, I can be pretty extroverted. You have to be adaptive around other people. It would be weird to be the same kind of person on a date and with my friends at the football game! (Harter, late adolescence)

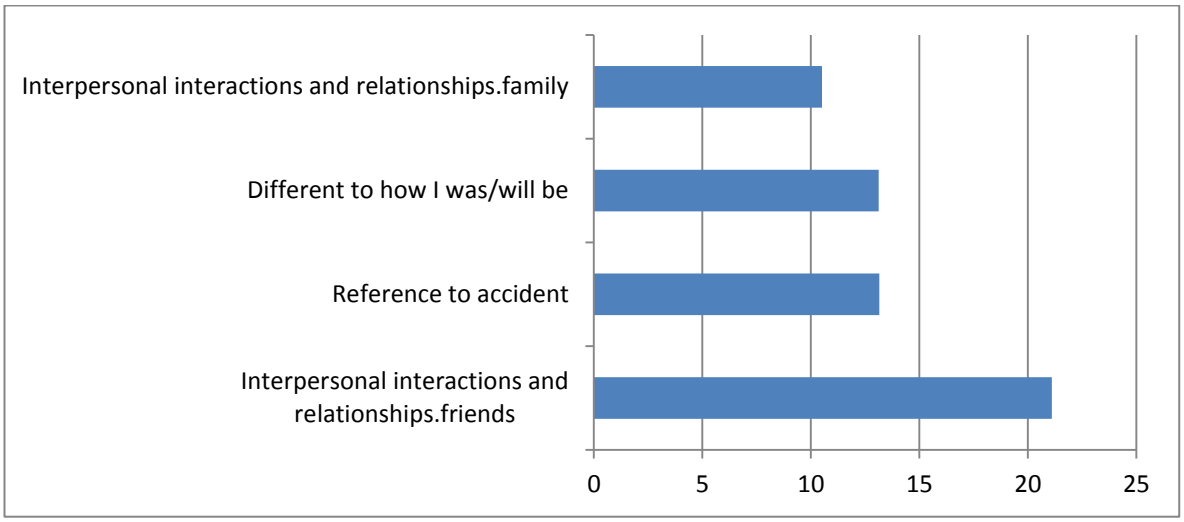

Figure 7-15: Debbie - common themes from SUI data

7.3.13 Stuart narrative themes (13 years 10 months at injury; 17 years at recruitment)

Stuart's narrative was longer than some and involved some detailed answers. The four main themes that emerged were (see Figure 7-16):

Change from how I was /will be

> *I'd also like to think the fact I'm sort of, I'm very close to my Mum and we get on really well and I'd like to think that'd stay the same like forever basically*

> *…the main reason I've changed from year 11 to year 12 is because I'm more sort of comfortable with people around me….I get on better with them and sort of the ones that I didn't like have been filtered out*

Psychosocial qualitites

> *In year 11 I was always sort of very very quiet. Whereas in sixth form, I'm a little bit louder, I'm not too loud*

> *I'm pretty down to earth*

Beliefs – political

> *I don't know it seems at school the way it seems is that more sort of loud and anti-education you are it seems the popular you are but I just couldn't care less about being popular*

> *…probably wouldn't work as hard at school obviously because I'd be at the end of the education for that sort of clique….I don't think it would make too*

much difference. I think it would probably make a bit of difference to my sort of like political standings and other things like that

Beliefs – society

…well cos well sort of cos yeah you can, you can take things too far, you can take any of the major world "baddies" if you like and they've all taken it too far. Take Hitler or someone similar if you lose your grip on reality you become arrogant, you become pigheaded, you become so many things that are just, I don't want to become them

…simple reason that I believe in collateral damage. No-one else.. everyone else is concerned with how the individual feels but I sort of see it as, well if I see a problem I'll just think what's going to be good on the whole

There is a qualitative similarity in the values outlined in Stuart's narrative and that of the normative sample below that is typical of his age:

..simple reason that I believe in collateral damage. No-one else.. everyone else is concerned with how the individual feels but I sort of see it as, well if I see a problem I'll just think what's going to be good on the whole, in the long run … I don't think anyone else ever looks that long term. Everyone's sort of concerned with the here and now and everyone sort of gets greedy but, no I don't think I'm anything like that (Stuart T1)

I've also become more religious as I've gotten older, not that I'm a saint or anything. Religion gives me a sense of purpose, in the larger scheme of things, and it provides me with personal guidelines for the kind of adult I'd like to be. For example, I'd like to be an ethical person who treats other people fairly. That's the kind of lawyer I'd like to be, too. (Harter, late adolescence)

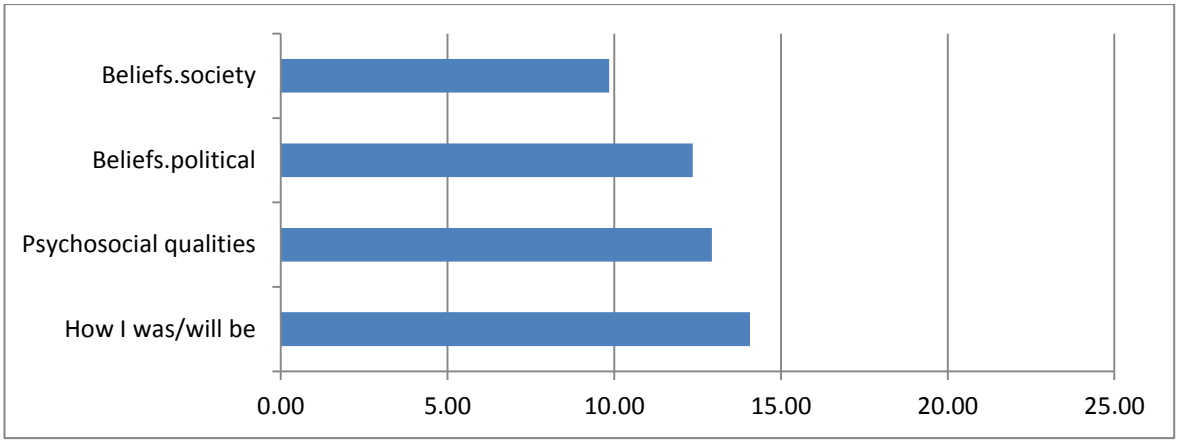

Figure 7-16: Stuart - common themes from SUI data

7.3.14 Rachel narrative themes (14 years 6 months at injury; 16 years at recruitment)

Rachel required regular prompting and explanation of questions. The four most common themes were (see Figure 7-17)

Physical qualities

I'm a girl…I've got brown hair

…scars…stick out and you can see them a mile off

Reference to accident

… knowing that I can still move my fingers as fast as I used to on the keyboard

…Cos I can stretch my fingers and do all the grooves and things

….Cos then I've got a movement that's connected to my arm and that means I can move my arm and me arms are connected to my body so I know I'll be able to walk

Health and well being of others

I want to be a person who is, who looks after animals and thinks about them and my Mum and Dad and Sam and if one of them's poorly go and look and go to them and check them over and see if they're alright

Being different to how I was/will be

(How were you different 5 years ago?)

Bit smaller

(How do you change from year to year?)

Grow taller and your hair changes colour

Rachel's descriptions of her physical self would be expected in a much younger child

I'm a girl…I've got brown hair

grow taller and your hair changes colour

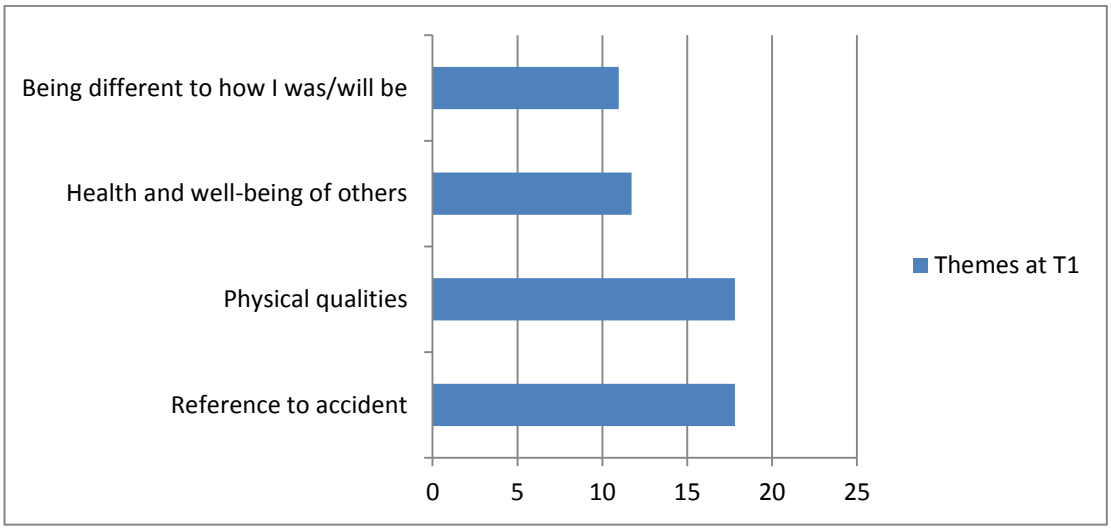

Figure 7-17: Rachel - common themes from SUI data

7.3.15 Dan narrative themes (9 years 6 months at injury; 10 years at recruitment)

The interview data was brief but two themes emerged (see Figure 7-18):

Interpersonal interactions and relationships

(Do you think there's anyone else who's exactly like you?)

(You're pointing to your Mum)

(Is she exactly like you?)

Yeah. Cos I love her and she loves me

Aspiration to be good at

Why do you want to be like Renaldo?

Good at football

Dan's interview lacked the comparative element to others that would have been expected at his age.

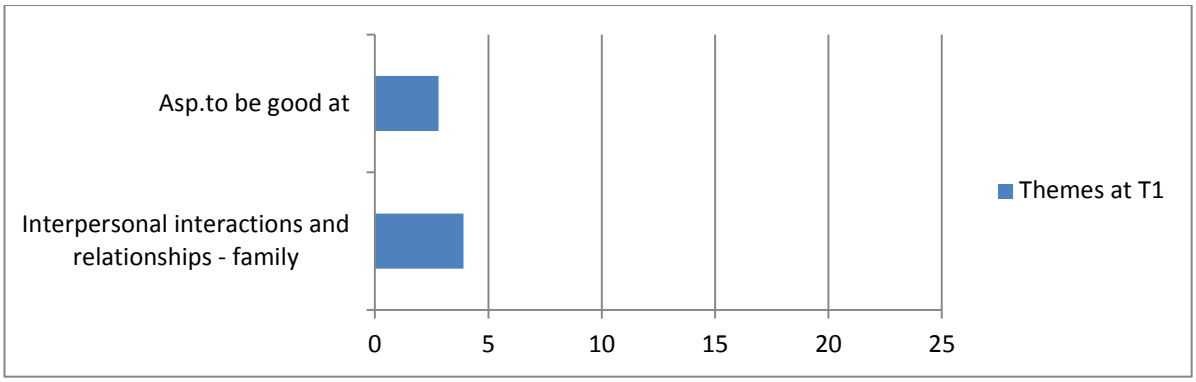

Figure 7-18: Dan - common themes from SUI data

7.4 Summary

This chapter has given more attention to the thematic analysis of the Self Understanding Interview data. The development of the thematic structure has been explained and the themes of the individual case results have been presented along with their comparison to typical children. This analysis has added to the second research question

2. *Compare the profile to typically developing children as reported in the literature*

When the data from the interviews were compared to that expected in typical development, much of the thematic structure was similar. Some of the participants mentioned their brain injury. Some also mentioned that the brain injury caused them to be different from how they used to be, as well as being different from others, such as their friends. However, much of the content included typical descriptions of themselves, such as their physical characteristics, and reference to their friends and family relationships.

The next chapter will present the data from the children who remained in the study until the third and fourth data collection visits in order to address the third and fourth research questions.

8 Chapter 8: Change over time results

8.1 Introduction

The longitudinal aspect of this research study will be presented in this chapter. The data presented here will be that of the ten children and young people who remained in the study for three or more visits i.e. T3 and T4. These data represent a period of 12-18 months and change over time is captured to address the second two research questions:

3. **Explore the profile of the ongoing development of self-awareness following TBI in childhood**
4. **Compare the ongoing profile to typically developing children**

The changes in the scores on the Harter Scales and SDQ are presented in relation to the norms and again Dan doesn't have SDQ self-report data due to his age.

8.2 Rupert - 3 visits (16 years 5 months at injury; 18 years at recruitment)

Over the three visits, Rupert left residential rehabilitation and moved to an extensively adapted property with his mother and her partner. On the second visit he had no recall of the first visit. On the third visit he had a structured week involving attendance at a local centre twice a week, physio twice a week and had plans to start at college 3 days a week to do art. He reported feeling happier and having a more positive mood than he had six months ago.

He reported less information about the brain and the consequences of brain injury at the second visit (15/22 at T1 and 11/22 at T2). He continued to have a sketchy recall of the accident that other people had told him.

More difficulties were reported at T2 (see Table 8-2). This was an accurate reflection of his ongoing profile of difficulties across domains that was observed by the researcher. However, speaking and concentrating were no longer reported as a difficulty. This was not endorsed by researcher as some of the interview recording continued to be unintelligible. The items "scholastic competence", "athletic competence" and "behavioural conduct" remained below the normative value across the three visits whereas "social competence" and "close friendship" reached the ceiling of 4.0 (see Figure 8-1) Many behavioural and emotional items remained stable over time and difficulties with "feelings and behaviours" were still not reported. This is endorsed by the "self-worth" self-report that was above the norm value (See figure 8-1). The "hyperactivity and attentional difficulties" item increased to **very high** (see Tables 8-1 and 8-2).

There was a mixed presentation in the interview data. The scoreable chunks of interview data changed at T2 and more of the chunks were assigned to the psychological domain, as expected at his age (see Figure 8-2). However, the weighted mean decreased from 2.0 to 1.8 and the modal level was 1 at T2 indicating that the chunks of data were factual with little elaboration. Although the theme of "psychosocial qualities" (see Figure 8-3) is typical of his age, the scores were similar to a much younger child (Damon & Hart,1988) as seen in the excerpt below:

> What would you like to be like, what kind of person do you want to be like?
> *Me, I want to be like myself*
> What kind of things do you hope for in life?
> *Pause a solid relationship*
> Why's that?
> *Cos someone I can trust*
> And why would that be good?
> *Don't know* *(Rupert T2)*

> When that happens, I get a little depressed because I don't like myself as a person. But I tell myself that it's natural to make mistakes, so I don't really question the fact that deep down inside, the real me is a moral person. Basically, I like who I am, so I don't stay depressed for long. (Harter pen portrait, late adolescence)

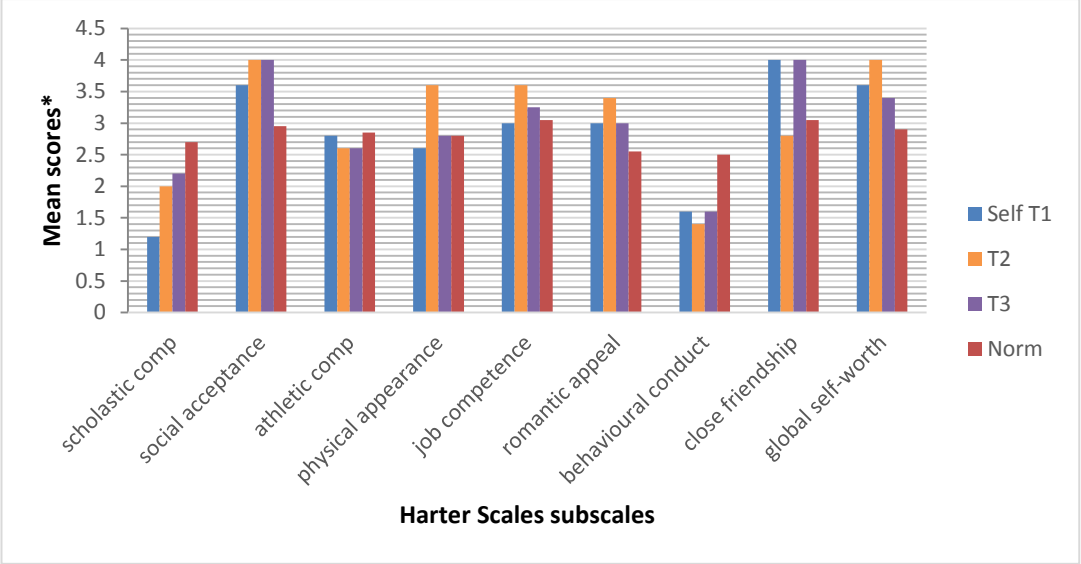

Figure 8-1: Rupert- repeated Harter Scale self-rating scores at T2 and T3 compared to normative data. *mean scores range 1-4

Table 8-1: Rupert repeated SDQ self-report scores. *Descriptors – very low, low, close to average, high, very high

Self-rating raw scores						
	T1	Descriptor *	T2	Descriptor	T3	Descriptor
SDQ overall stress	10	Close to average	8	Close to average	12	Close to average
Emotional distress	1	Close to average	0	Close to average	0	Close to average
Behavioural difficulties	1	Close to average	2	Close to average	2	Close to average
Hyperactivity and attentional difficulties	7	High	4	Close to average	8	Very high
Difficulties getting along with other children	1	Close to average	2	Close to average	2	Close to average
Kind and helpful behaviour	5	Low	9	Close to average	10	Close to average

Table 8-2: Rupert repeated KIC self-report scores

Problems identified	T1 self-report	T2 self-report
Concentrating	Yes	No
Getting tired easily	Yes	Yes
Remembering things	Yes	Yes
Keeping up with the rest of the class	No	Yes
Planning things, getting organized	Don't know	Yes
Walking problems	Yes	Yes
Writing problems	No	Yes
Speaking or talking	Yes	No
Saying sentences so they make sense	Yes	Yes
Understanding what other people say	No	Yes
Reading	Yes	Yes
Feelings and behaviour	No	No

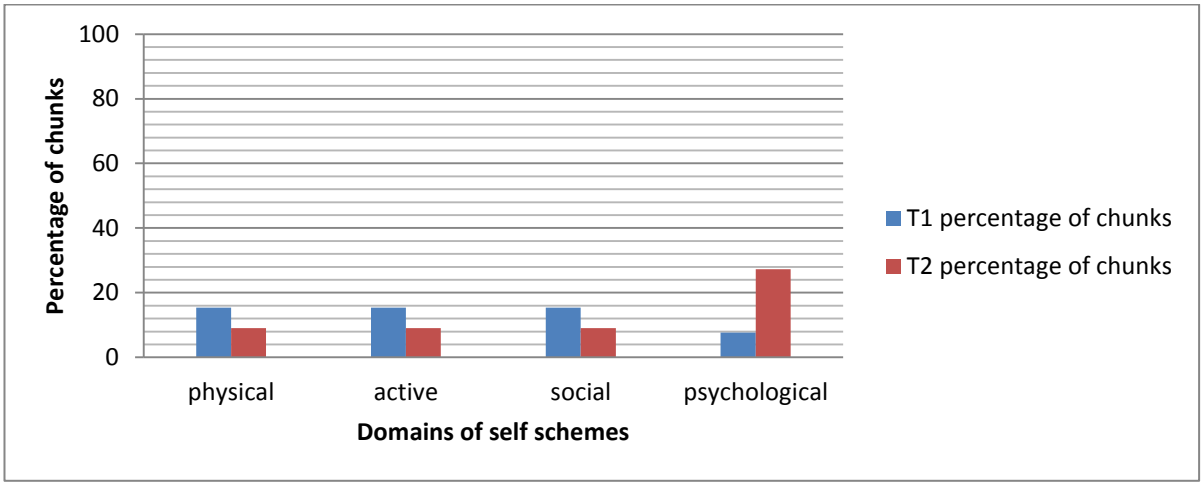

Figure 8-2: Rupert Percentage of SUI chunks coded to each domain at T1 and T2

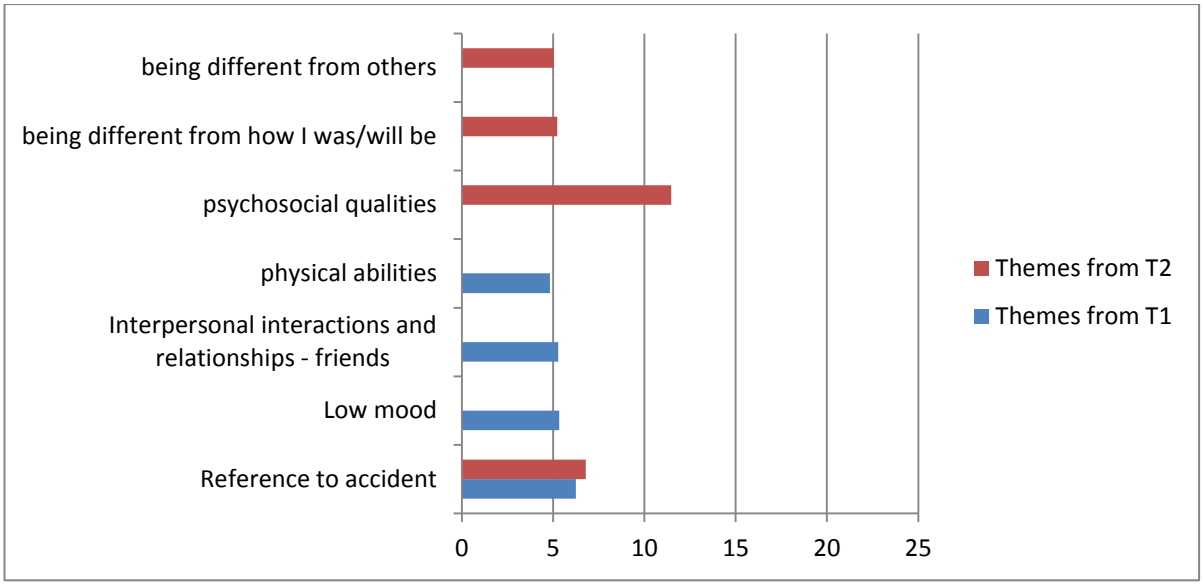

Figure 8-3: Rupert repeated SUI themes data

8.3 Henry – 3 visits (10 years 1 month at injury; 13 years at recruitment)

Henry remained at the same school throughout the study. He changed school year but reported few other changes.

Henry reported a simlar profile of difficulties across the three visits (see Table 8-4). He reported a slightly higher level of "behaviour difficulties" at T3 and although the reported "difficulties getting along with other children" increased at T2, it was rated **close to average** at T3 (see Table 8-3). Five of the nine items on the Harter Scales were scored at the maximum value of 4.0 at T1. All of these were rated lower at the subsequent visits and six items remained above the normative value at T3 (see Figure 8-4). "Romantic appeal" was the greatest negative discrepancy at T3 with Henry rating himself below the norm.

There was a change in the interview data. There were more scoreable chunks assigned to the psychological domain (see Figure 8-5), the weighted mean increased from 2.1 to 2.3 and the modal level increased from 1 to 3. These increases indicated that Henry was giving more elaborate responses, more like his age. The themes at T2 included psychological qualities and some indication of values and beliefs that again would be more typical of his age (see Figure 8-6). However, the style of the narrative was more like a younger child:

> And what about in the future, what kind of person do you want to be?
> *Just a nice person*
> Why?

Because it's good to be a nice person, people might not (don't want to say that again – it's ok) like you if you're a nasty person and you won't have any friends *(Henry T2)*

I act really dumb and say things that are just plain stupid. Then I worry about what they must think of me, probably that I'm a total dork. (Harter, early adolescence)

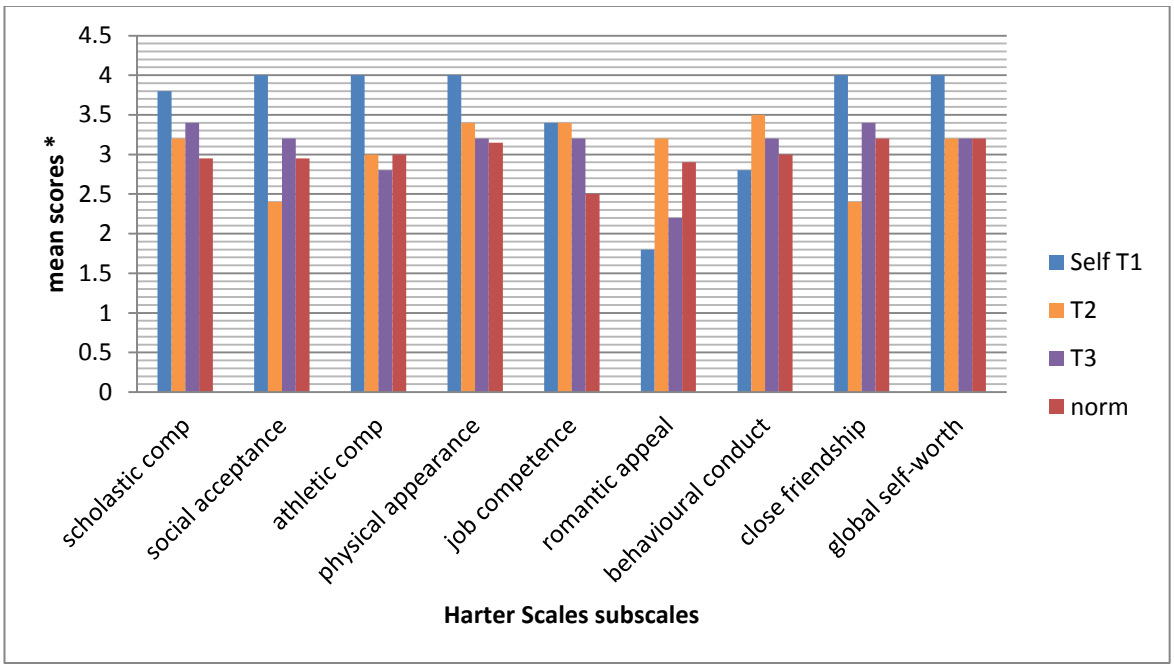

Figure 8-4: Henry repeated Harter Scales self-rating scores at T1, T2 and T3. *Mean scores range 1-4

Table 8-3: Henry repeated SDQ self-report scores at T1,2 and 3. *Descriptors – very low, low, close to average, high, very high

Self-report raw scores						
	T1	Descriptor*	T2	Descriptor	T3	Descriptors
SDQ overall stress	12	Close to average	11	Close to average	11	Close to average
Emotional distress	2	Close to average	2	Close to average	2	Close to average
Behavioural difficulties	2	Close to average	2	Close to average	4	Slightly raised
Hyperactivity and attentional difficulties	4	Close to average	2	Close to average	4	Close to average
Difficulties getting along with other children	4	High	5	Very high	1	Close to average
Kind and helpful behaviour	8	Close to average	9	Close to average	7	Close to average

Table 8-4: Henry repeated KIC self-report scores at T1 and 2

Problems identified	T1 self-report	T2 self-report
Concentrating	Yes	Yes
Getting tired easily	Yes	Yes
Remembering things	Yes	Yes
Keeping up with the rest of the class	No	No
Planning things, getting organized	No	No
Walking problems	No	No
Writing problems	No	No
Speaking or talking	No	No
Saying sentences so they make sense	No	No
Understanding what other people say	No	No
Reading	No	No
Feelings and behaviour	No	No

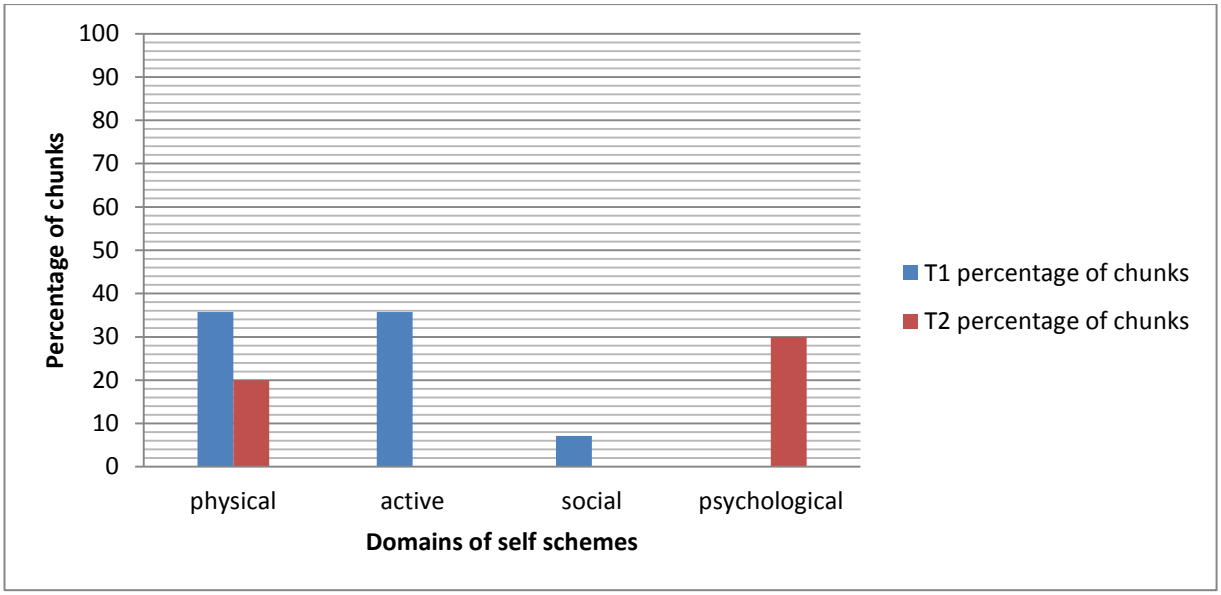

Figure 8-5: Henry- percentage of SUI chunks coded to each domain at T1 and 2

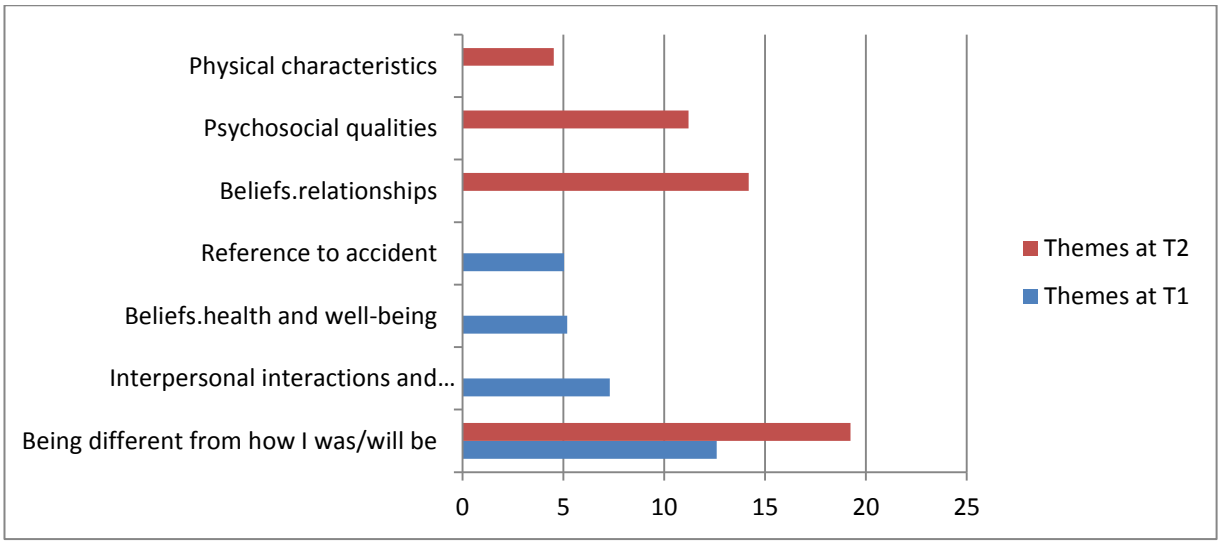

Figure 8-6: Henry SUI themes at T1 and 2

8.4 Amelia – 4 visits (16 years 5 months at injury; 19 years at recruitment)

On subsequent visits Amelia had left school and started college, while working part time in the supermarket. She then left college and worked full time at the supermarket. She initially used the leisure centre but was too tired after work and gave up the membership. She passed her BTec modules and passed her driving test. Her mother continued to work away at times and her relationship with her father became more distant. Her brother lived at home and they continued to argue but got on ok. On the final visit she had a new group of friends and was socializing a lot – she stated that she was "getting too drunk".

There was an increase in her knowledge of brain injury and her narrative of events. She still relied on others' reports and could not remember the accident first hand. The knowledge scores of the KIC increased from 17/22 (some missing data) to 20/24

Over time, Amelia's profile changed across domains. The self-ratings increased in many areas. There was an overall increase in self-worth which was endorsed in decreasing scores on the SDQ to the **average** range (see Table 8-5). The only self-reported area of concern on the KIC was "remembering things" (see Table 8-6). The final Harter self-ratings were above the norm in all areas with the exception of "romantic appeal" (see Figure 8-7). Amelia made reference to this theme in her interview:

> *it's just I don't have good relationships with boys and they seem to be like scared by me (T1)*

The quality of the narrative changed over time. The responses were longer and fuller. Less prompting and probing was required.

The interview chunks continued to reflect the normative profile of more items in the psychological domain (see Figure 8.8). The weighted mean increased from 2.5 to 2.9 and the modal level increased to 4. The later themes of psychosocial qualities and beliefs reflected a greater age-related ability to make values and theories about the world while looking to the future (see Figure 8.9).

> *I hope to earn lots of money and so I'll have to work hard to be that, which I don't mind doing, cos then you get a good outcome, just to be good at what I do*
>
> And what makes it good for you to work hard and so on?
>
> *Cos then I think the company then respects you for what you do cos you're doing a good job at it and then you get a better pay for what you're doing*
>
> Eventually I want to go to law school, so developing good study habits and getting top grades are both essential. (My parents don't want me to become a lawyer; they'd rather I go into teaching, but law is what I want to pursue.) (Harter, late adolescence

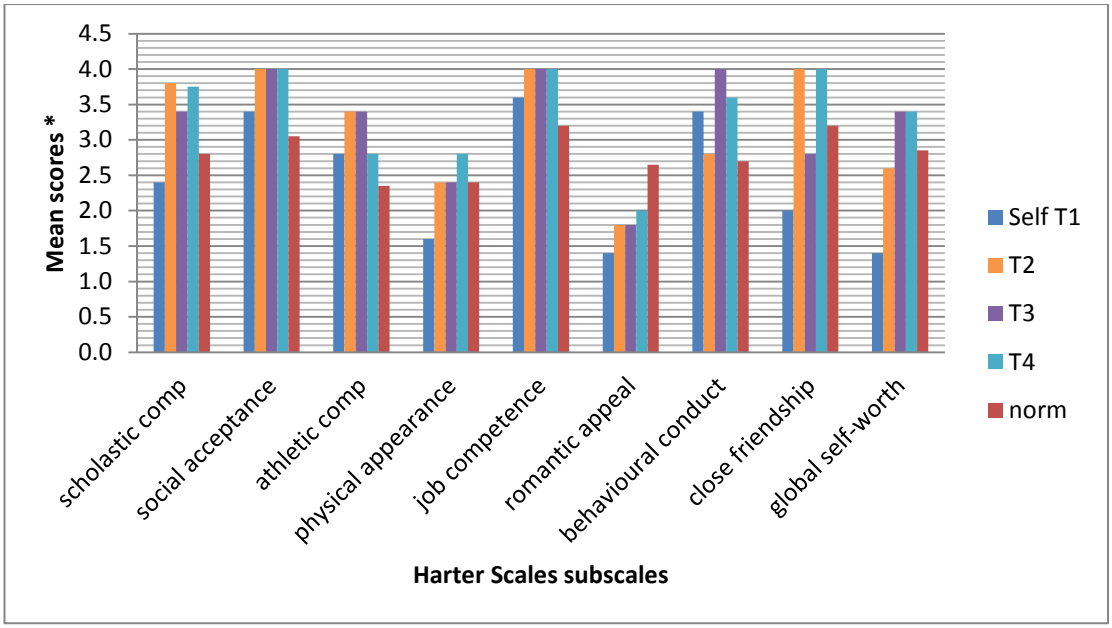

Figure 8-7: Amelia repeated Harter Scales self-report scores at T1, 2, 3 and 4. *Mean scores range 1-4

Table 8-5: Amelia repeated SDQ self-report scores at T1, 2, 3 and 4. *Descriptors – very low, low, close to average, high, very high

Self-report raw scores								
	T1	Descriptor *	T2	Descriptor	T3	Descriptor	T4	Descriptor
SDQ overall stress	12	Close to average	13	Close to average	9	Close to average	5	Close to average
Emotional distress	7	Very high	8	Very high	4	Close to average	1	Close to average
Behavioural difficulties	1	Close to average	1	Close to average	0	Close to average	0	Close to average
Hyperactivity and attentional difficulties	1	Close to average	2	Close to average	3	Close to average	2	Close to average
Difficulties getting along with other children	3	Slightly raised	2	Close to average	2	Close to average	2	Close to average
Kind and helpful behaviour	8	Close to average	7	Close to average	5	Low	8	Close to average

Table 8-6: Amelia repeated KIC scores at T1, 2 and 4

Problems identified	T1 self-report	T2 self-report	T4 self-report
Concentrating	No	Yes	No
Getting tired easily	Yes	No	No
Remembering things	Yes	No	Yes
Keeping up with the rest of the class	No	No	No
Planning things, getting organized	No	No	No
Walking problems	No	No	No
Writing problems	No	No	No
Speaking or talking	No	No	No
Saying sentences so they make sense	No	No	No
Understanding what other people say	Yes	No	No
Reading	No	No	No
Feelings and behaviour	Yes	No	No

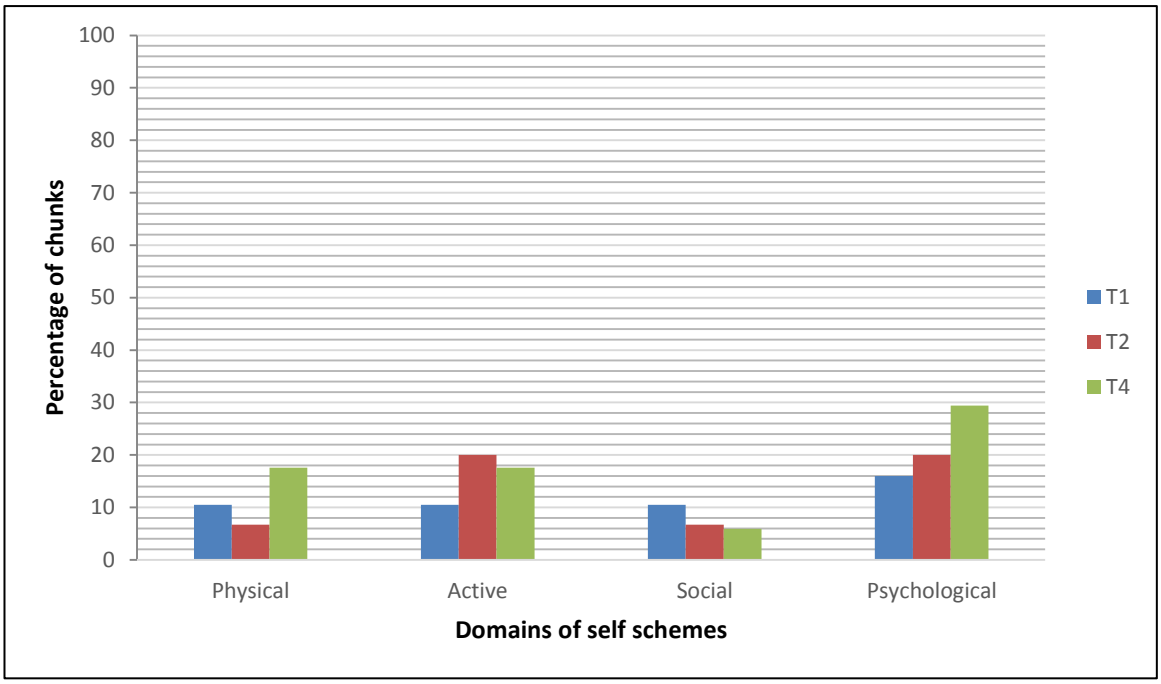

Figure 8-8: Amelia – percentage of SUI chunks data coded to each domains at T1, 2 and 4

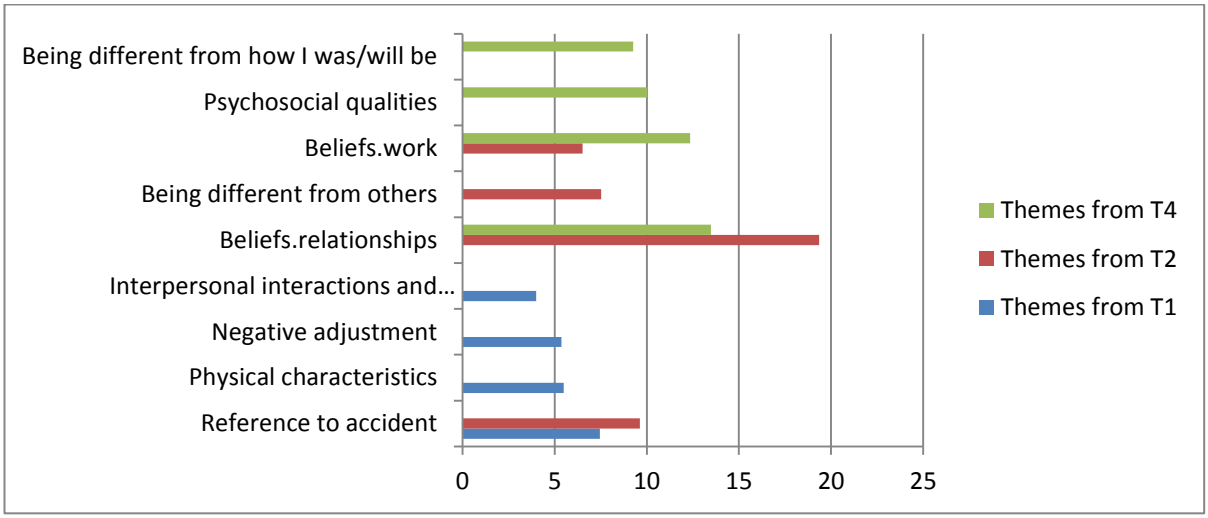

Figure 8-9: Amelia repeated SUI themes data at T1, 2 and 4

8.5 Lee – 4 visits (17 years 1 month at injury; 18 years at recruitment)

Lee moved from rehabilitation to new home address with his mother, stepfather and stepsister. The new flat was in the same residential area and he still had access to his old friends etc. He had rehabilitation workers in the home but there was a high turnover of staff. He had ongoing physiotherapy following a programme at the gym. He also had ongoing speech and language therapy. The legal case came to court during the research programme.

His knowledge of his own accident and the effects of brain injury remained the same. He remembered events of the day of the accident and then relied on information passed on from others.

Although there was change in the self-ratings on the Harter scales over time, none of the items reached the ceiling of 4,0 with "athletic competence" the lowest score at T4 (see Figure 8-10). Lee continued to have physical difficulties at T4 and was still seeing a physiotherapist and going to the gym with his rehabilitation assistant.

The emotional and behavioural items on the SDQ changed over time (see Table 8-7). The self-rating score on the emotional items reduced but the "getting on with other children" item was scored as more of a problem. The "feelings and behavior" item on the KIC was also scored on self-report as no longer a problem at T4 (see Table 8-8). The other communication items that were previously not endorsed at T1 were acknowledged at T4. Lee continued to have communication difficulties during the interviews and had been attending community speech and language services.

There was a change in the themes of the interviews. At T2 there was a clear dominance of the themes of the accident and of being different from others (see Figure 8-12). Lee had just returned home after a long period of rehabilitation and was more acutely aware of the differences that he was facing in his daily life. At T4 Lee spoke more about his aspirations and beliefs, responding more fully to the questions in the semi-structured interview and reaching a maximum score of 4.0 at times. The weighted mean at T1 was 1.3 and increased to 2.6 at T4. The quantity of chunks assigned to the psychological domain (see Figure 8-11) increased over time and reflected a more age-appropriate dominance. However, the interview still lacked overall evidence of elaboration expected at this age and some answers remained short and basic, more like a younger child:

Obviously like I'm just cool

What does that say about you that you're just cool?

It's nice to be cool isn't it?

Is it important to be cool and likeable?

Yeah obviously, why not?

Why not, why?

Otherwise you'd be on your own like, init

Then you won't be on your own?

If you're not cool and you're not likeable then you're on your own init (T4)

I'm pretty much being the kind of person I want to be. I'm doing well at things that are important to me like getting good grades. That's what is probably *most* important to me right now. Having a lot of friends isn't that important to me. I wouldn't say I was unpopular, though. While I am basically an introvert, especially on a date when I get pretty self-conscious, in the right social situation, like watching a ball game with my friends, I can be pretty extroverted (Harter, late adolescence)

I'm an extrovert with my friends: I'm talkative, pretty rowdy, and funny. I'm fairly good-looking if I do say so. All in all, around people I know pretty well I'm awesome, at least I think my friends think I am. I'm usually cheerful when I'm with my friends, happy and excited to be doing things with them. I like myself a lot when I'm around my friends. (Harter, early adolescence)

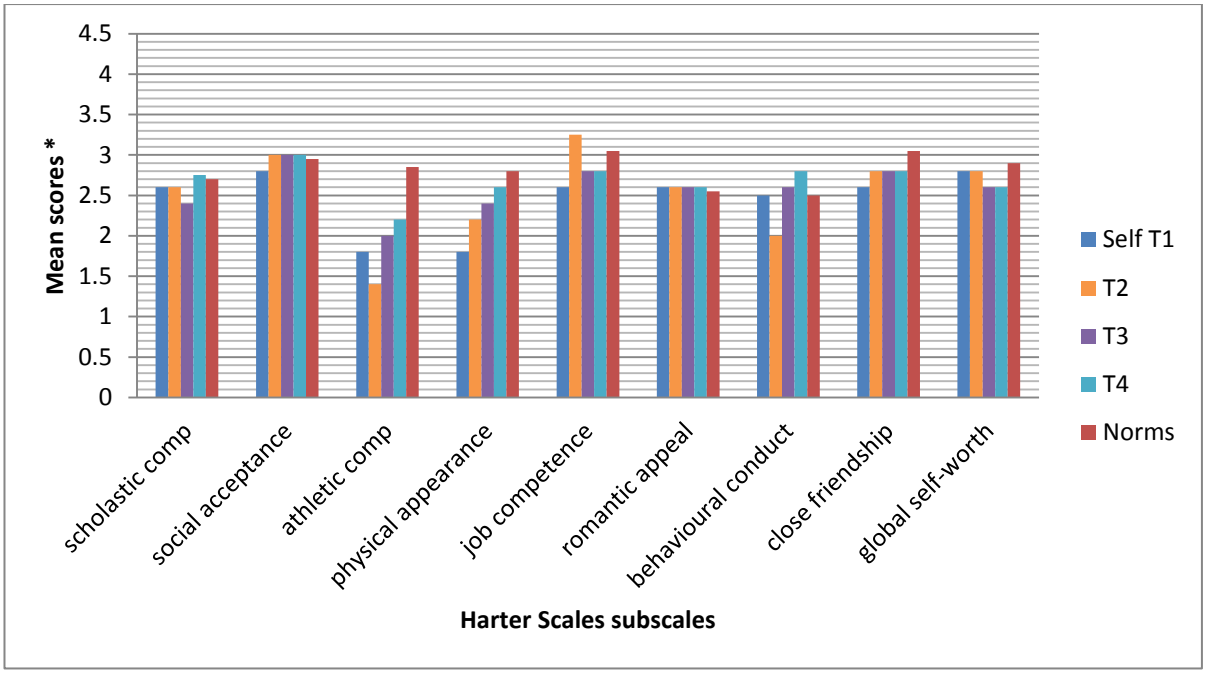

Figure 8-10: Lee repeated Harter Scales self-rating scores at T1, 2, 3 and 4. *Mean scores range 1-4

Table 8-7: Lee repeated SDQ self-rating scores at T1, 2, 3 and 4. *Descriptors – very low, low, close to average, high, very high

Self-rating raw scores								
	T1	Descriptor*	T2	Descriptor	T3	Descriptor	T4	Descriptor
SDQ overall stress	14	Close to average	15	Slightly raised	9	Close to average	12	Close to average
Emotional distress	4	Close to average	3	Close to average	2	Close to average	3	Close to average
Behavioural difficulties	3	Close to average	4	Slightly raised	1	Close to average	1	Close to average
Hyperactivity and attentional difficulties	5	Close to average	6	Slightly raised	4	Close to average	5	Close to average
Difficulties getting along with other children	2	Close to average	2	Close to average	2	Close to average	3	Slightly raised
Kind and helpful behaviour	8	Close to average	7	Close to average	8	Close to average	5	Low

Table 8-8: Lee repeated KIC self-report scores at T1, 2 and 4

Problems identified	T1 self-report	T2 self-report	T4 self-report
Concentrating	Yes	Yes	Yes
Getting tired easily	Yes	Yes	Yes
Remembering things	Yes	Yes	Yes
Keeping up with the rest of the class	No	Yes	Yes
Planning things, getting organized	No	Yes	Yes
Walking problems	Yes	Yes	Yes
Writing problems	Yes	Yes	Yes
Speaking or talking	Yes	Yes	Yes
Saying sentences so they make sense	No	Yes	Yes
Understanding what other people say	No	Yes	Yes
Reading	No	Yes	No
Feelings and behaviour	Yes	Yes	No

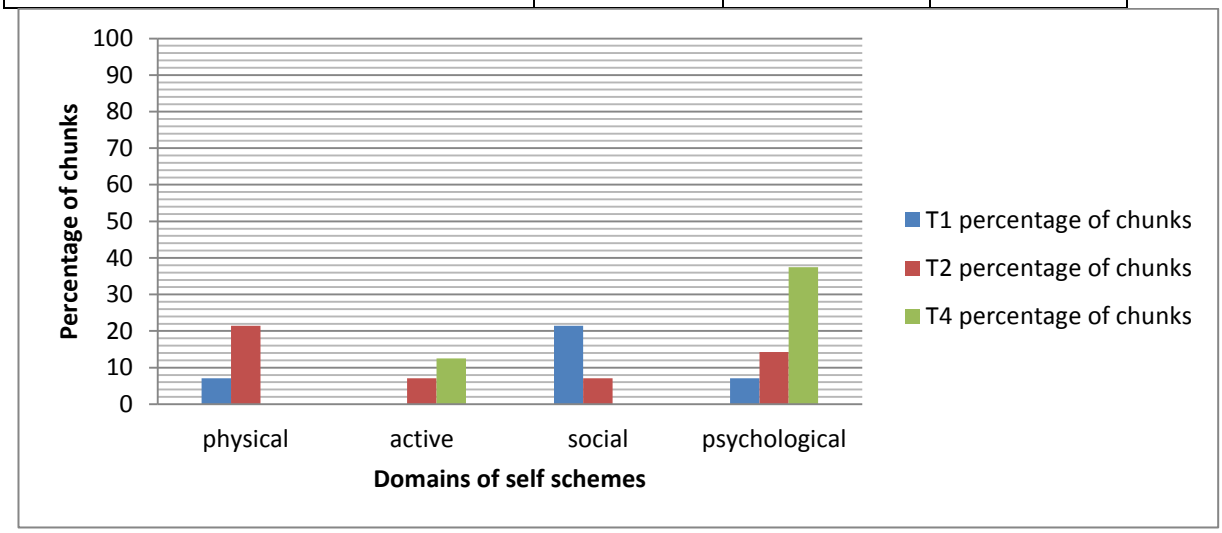

Figure 8-11: Lee - Percentage of SUI chunks data coded to each of the domains at T1, 2 and 4

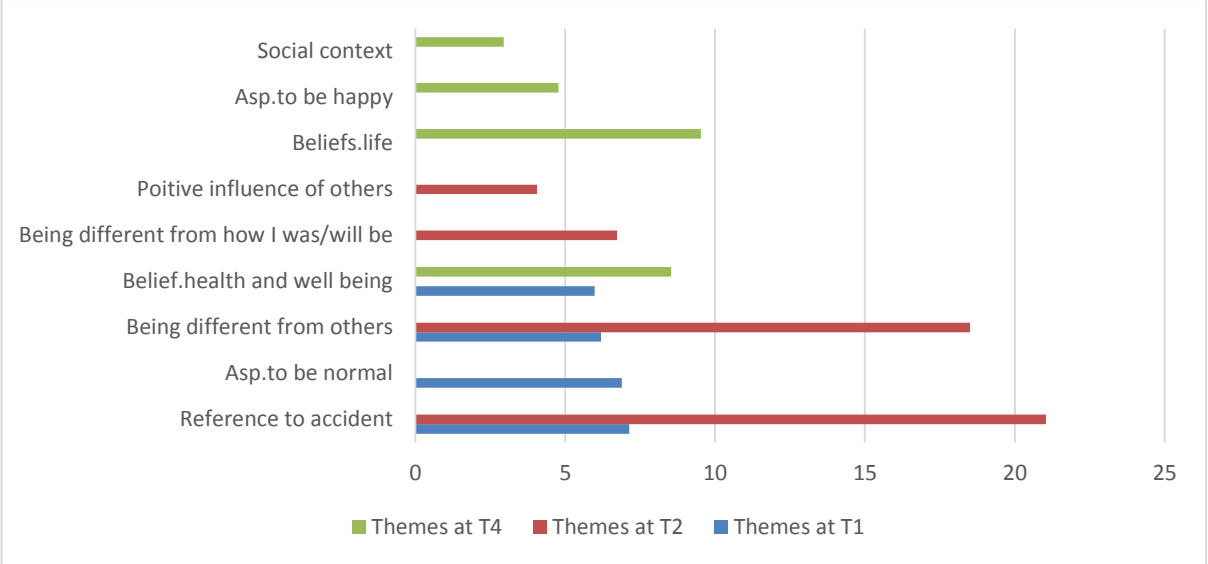

Figure 8-12: Lee repeated SUI themes data at T1, 2 and 4

8.6 Robert – 4 visits (13 years 2 months at injury;17 years at recruitment)

Robert finished school during the research project. At the final visit, his mother had structured his week with volunteer opportunities and recreational activities – horse-riding and swimming. He was spending one day a week at his grandma's. He had graduated from school and attended the ball. He had also carried the Olympic torch. He asked to skip some questions on the self-report measures increasingly over the visits (3 at T1, 5 at T3 and 9 at T4). The mean scores were calculated on the available data.

Over the four time-points there was some change in presentation. Some of the Harter scores reached the ceiling or close to it – "social competence" and "close friendship". Reporting of the "hyperactivity and attentional difficulties" item on the SDQ increased to a very high score (see Table 8-9). Different items were reported as difficult on the KIC over time. "Reading" and "keeping up with the rest of the class" were no longer reported at T4 but "Feelings and behaviour" "remembering things" and "understanding what people say" were noted as difficulties that were not reported earlier (see Table 8-10).

Overall the pattern of scored chunks in the interview data fell into the psychological domain. This is typical of a young person Robert's age (see Figure 8-14). However, the mean score from the data remained below 2 indicating that the responses in the interview lacked elaboration and did not change over time. These simple responses lack the elements that would be expected at his age. These responses are more like a younger child, but perhaps it was communication difficulties.

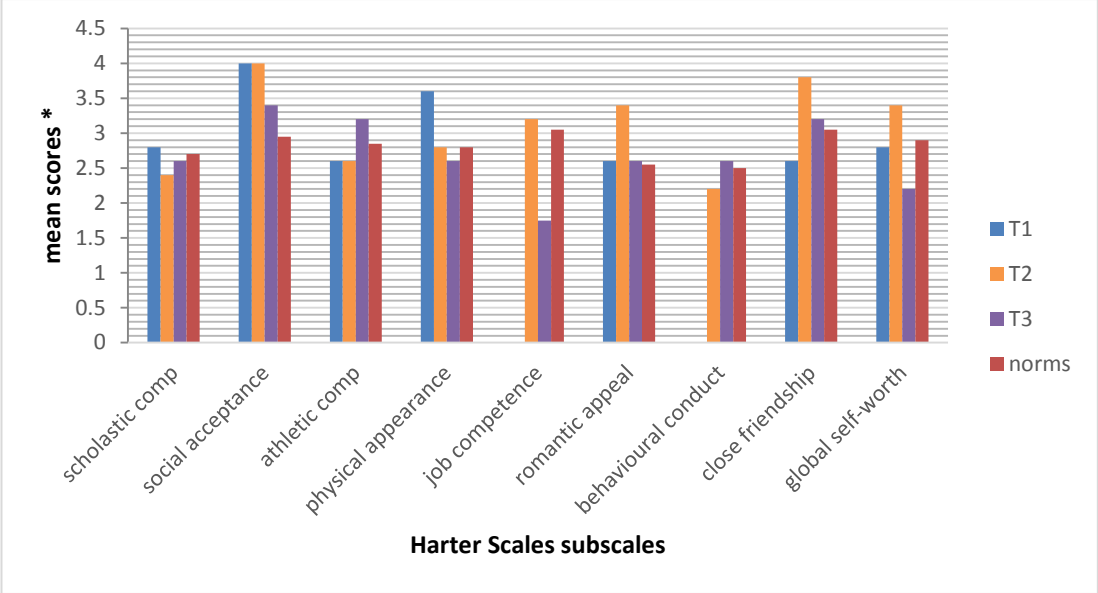

Figure 8-13: Robert Harter Scales self-report scores at T1, 2 and 3. *mean scores range 1-4

Table 8-9: Robert repeated SDQ self-rating scores at T1, 2, 3 and 4. *Descriptors – very low, low, close to average, high, very high

Self-rating raw scores								
	T1	Descriptor*	T2	Descriptor	T3	Descriptor	T4	Descriptor
SDQ overall stress	11	Close to average	14	Close to average	12	Close to average	16	Slightly raised
Emotional distress	0	Close to average	5	Slightly raised	0	Close to average	2	Close to average
Behavioural difficulties	4	Slightly raised	2	Close to average	3	Close to average	3	Close to average
Hyperactivity and attentional difficulties	6	Slightly raised	7	High	9	Very high	9	Very high
Difficulties getting along with other children	1	Close to average	0	Close to average	0	Close to average	2	Close to average
Kind and helpful behaviour	6	Slightly low	9	Close to average	8	Close to average	10	Close to average

Table 8-10: Robert repeated KIC self-report scores at T1, 2 and 4

Problems identified	T1 self-report	T2 self-report	T4 self-report
Concentrating	Yes	Yes	Yes
Getting tired easily	Yes	Yes	Yes
Remembering things	No	Yes	Yes
Keeping up with the rest of the class	Yes	No	No
Planning things, getting organized	Yes	Yes	Yes
Walking problems	Yes	Yes	Yes
Writing problems	Yes	Yes	Yes
Speaking or talking	Yes	No	Yes
Saying sentences so they make sense	Yes	Yes	Yes
Understanding what other people say	No	No	Yes
Reading	Yes	No	No
Feelings and behaviour	No	No	Yes

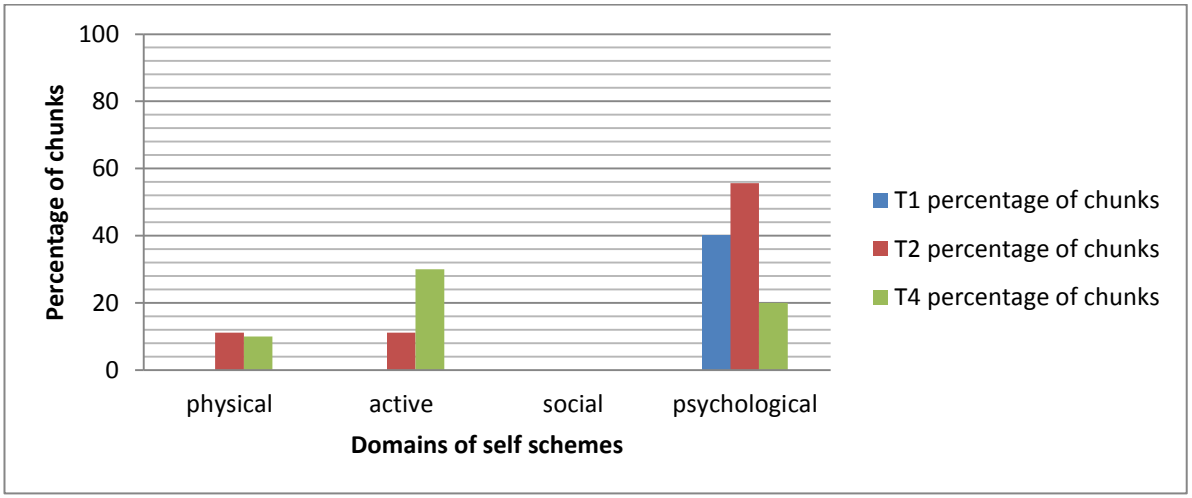

Figure 8-14: Robert – percentage of SUI chunks coded to each domain at T1, 2 and 4

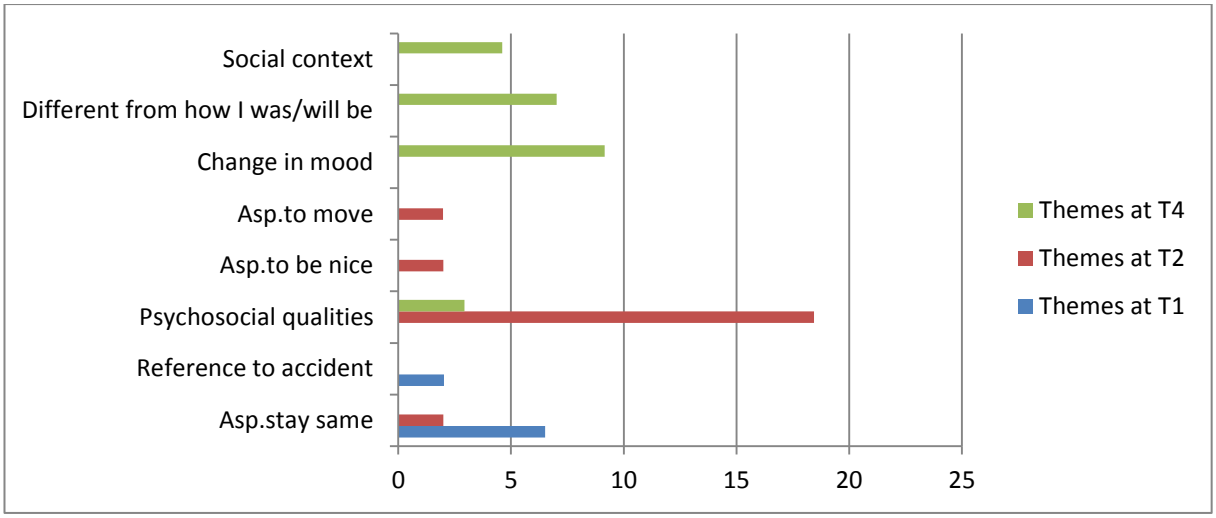

Figure 8-15: Robert repeated SUI themes data at T1, 2 and 4

8.7 Tracey – 4 visits (14 years 11 months at injury; 19 years at recruitment)

Tracey moved to university during the research study. At each of the subsequent visits, she arranged the visits independently but then forgot and had to be wakened by security in the student residences. She stated that she was enjoying student life and was often drinking until late. She had her legal case settled and had plans to invest the money with her father. She had learning support at university and paid domestic help. She continued to have observable physical difficulties.

The "close friendship" item reached the ceiling of 4.0 and the "behavioural conduct" and "job competence" items were also scored highly, close to the ceiling. These items were above the norm value. The only item that was not greater than or equal to the norm value was "athletic competence" (see Figure 8-16). Tracey continued to have chronic physical difficulties at T4.

Tracey's responses to the questions in the KIC and SDQ were consistent over time. The only difficulty that she additionally reported was "reading" (see Tables 8-11 and

8-12). She elaborated that it was difficult because of a visual difficulty. Visual problems were evident in the cooking task.

The narrative chunks of data that were scored were assigned more to the psychological domain at T4. This pattern is typical of children her age (see Figure 8-17). Although "reference to accident" was a common theme at all of the time points, at T1 it was not as common as others, whereas at T2 it was a dominant theme. Although it continued to be a theme at T4, it was not as dominant as at T2 and "psychosocial" theme emerged as a greater concern. Aspirations and beliefs continued to be common themes which are typical for her age (see Figure 8-18). The chunks of narrative data that could be scored reached the highest level of 4 reflecting the presence of beliefs and plans.

The interviews continued to flow and contain full answers with little prompting. There was evidence of the type of self-reflection typical of her age:

> *I don't really do things that are good for me! I do the opposite. Good for me right now would be to quit smoking, not going out as much and drinking as much alcohol. Eating vegetables, bla, bla, bla, all the things that I should be doing but I'm not doing.*
>
> Are they the only sort of things that are good for you or… are there other things in life that are good for you?
>
> *I think that a social life is good for you, I find that. Other people I have seen find that if they're stuck indoors they get a bit depressed. I try to have, I go out at least 4 nights a week, I try to think a social life is good (T4)*

Every now and then I get a little lackadaisical and don't complete an assignment as thoroughly or thoughtfully as I could, particularly if our high school has a big football or basketball game that I want to go to with my friends. But that's normal, I mean, you can't just be a total grind. You'd be pretty boring if you were. (Harter, late adolescence)

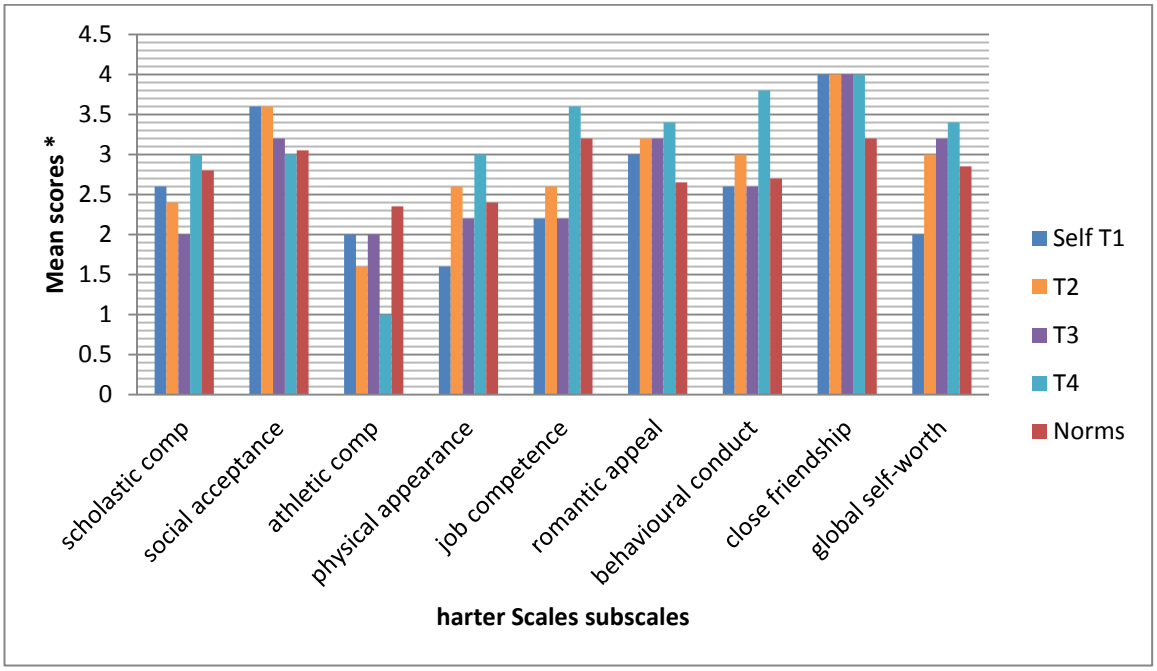

Figure 8-16: Tracey repeated Harter Scales self-rating scores at T1, 2, 3 and 4. *mean scores range 1-4

Table 8-11: Tracey repeated SDQ self-report scores at T1, 2, 3 and 4. *Descriptors – very low, low, close to average, high, very high

Self-report raw data								
	T1	Descriptor*	T2	Descriptor	T3	Descriptor	T4	Descriptor
SDQ overall stress	11	Close to average	7	Close to average	6	Close to average	4	Close to average
Emotional distress	5	Slightly raised	1	Close to average	1	Close to average	0	Close to average
Behavioural difficulties	3	Close to average	3	Close to average	2	Close to average	1	Close to average
Hyperactivity and attentional difficulties	3	Close to average	3	Close to average	3	Close to average	3	Close to average
Difficulties getting along with other children	0	Close to average	0	Close to average	0	Close to average	0	Close to average
Kind and helpful behaviour	10	Close to average	9	Close to average	9	Close to average	10	Close to average

Table 8-12: Tracey repeated KIC self-report scores at T1, 2 and 4

Problems identified	T1 Self-report	T2 Self-report	T4 Self-report
Concentrating	Yes	Yes	Yes
Getting tired easily	Yes	Yes	Yes
Remembering things	No	No	No
Keeping up with the rest of the class	Yes	Yes	Yes
Planning things, getting organized	Yes	Yes	Yes
Walking problems	Yes	Yes	Yes
Writing problems	No	No	No
Speaking or talking	No	No	No
Saying sentences so they make sense	No	No	No
Understanding what other people say	No	No	No
Reading	No	Yes	Yes
Feelings and behaviour	No	No	No

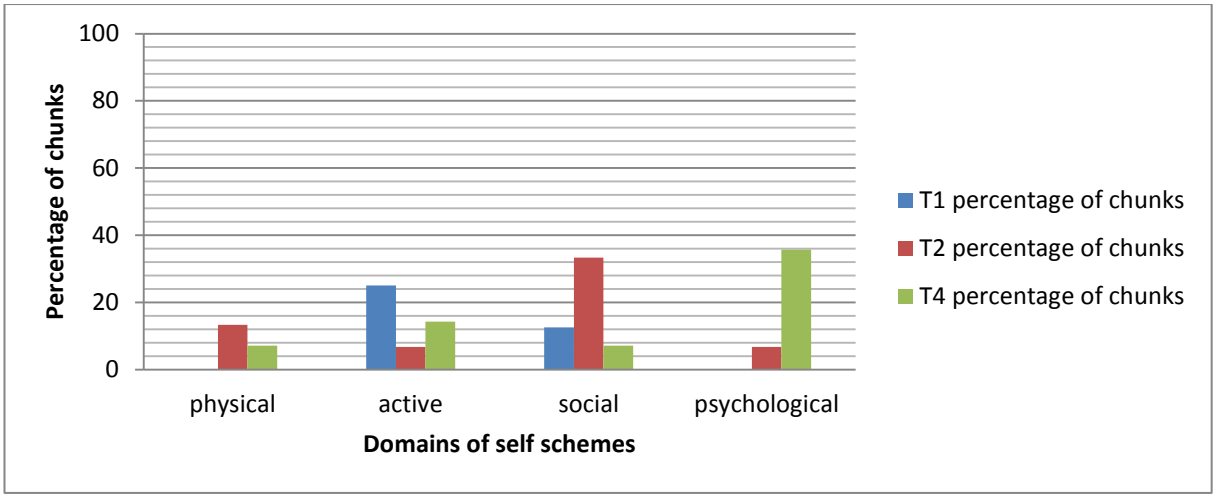

Figure 8-17: Tracey – percentage of SUI chunks data coded to each domains at T1, 2 and 4

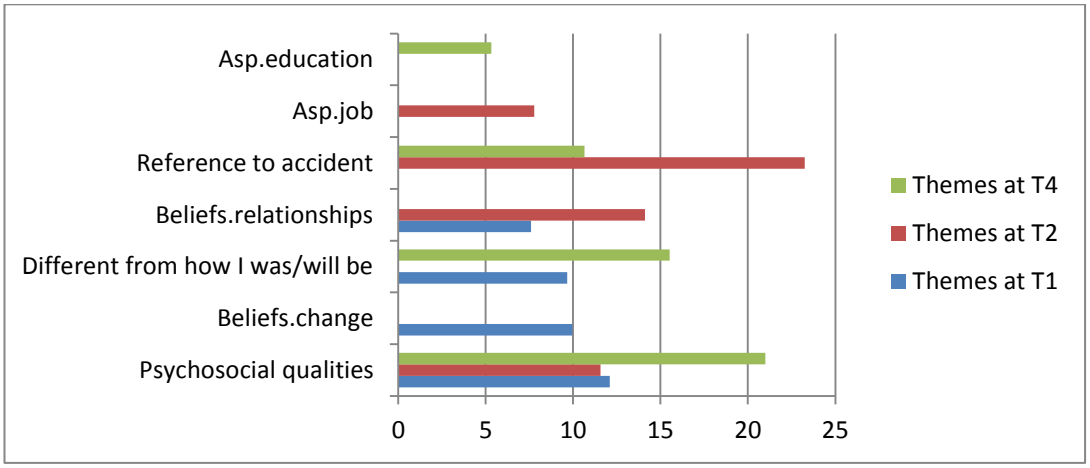

Figure 8-18: Tracey repeated SUI themes data at T1, 2 and 4

8.8 Debbie – 4 visits (17 years at injury; 18 years at recruitment)

Debbie had another opportunity for residential rehabilitation in an adult setting but only stayed four weeks and could not settle. She continued to have hydrotherapy and went to gym weekly. She had support worker from Headway 3xweek. She had a boyfriend who remained constant across the research study. At T3 she wasn't sure what to do regarding education etc and at T4 she had a clearer plan to start doing more in the New Year reflecting that the previous two years felt like a bit of a

rest and that she was ready to start again. In the interview narrative she explained some of the difficulties she had with relationships and how she would like to resolve some of the conflict.

Debbie continued to have little recall of her accident but she had a more complete and fluent narrative at T4. She continued to have little knowledge of brain injury and its consequences.

None of the Harter self-report items reached the ceiling of 4.0 across any of the time points. The items "scholastic competence" and "athletic competence" remained below the norm value throughout the four data points. The item "close friendship" was initially higher than the norm value but was below at the final time point (see Figure 8-19). More items were reported as difficulties at the final time point (see Table 8-14) and more behaviour difficulties were reported on the SDQ (see Table 8-13). The interview data continued to have scoreable chunks in the active, social and psychological domains, and at the final time point contained more data in the psychological domain as expected at Debbie's age (see Figure 20). The weighted mean increased over time and the narrative was more elaborate. The scoreable chunks were at a ceiling level of 4 and indicated full responses with some beliefs and plans expected at this age. She continued to have reference to the accident as a main theme but the final interview also included aspirations and goals with a more positive outlook more reflective of her age (see Figure 8-21).

What do you hope for in life, if you had 3 wishes?

Back to college, erm to go back to college, to make amends with everyone really from the past even if like just to settle it just to say sorry and all of that but and just to start afresh really like to start making a life ….just want to start fresh again like from the start of the New Year I just want to get back into it. Because the last 2 years it's basically been a rest for me and so the start of next year I'm gonna start proper like do stuff for myself instead of like thinking of people and start doing it myself (T4)

I'm looking forward to leaving home and going to college, where I can be more independent, although I'm a little ambivalent. I love my parents, and really want to stay connected to them, plus, what they think about me is still really important to how I feel about myself as a person (Harter, late adolescence).

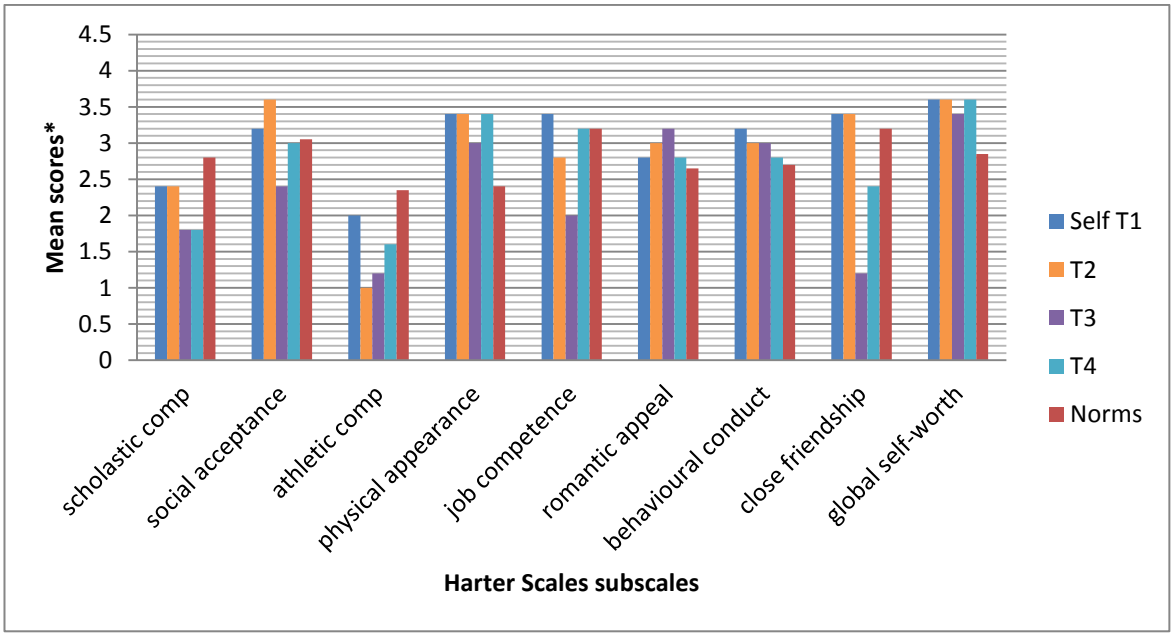

Figure 8-19: Debbie repeated Harter Scales self-rating scores an T1, 2, 3 and 4. *mean scores range 1-4

Table 8-13: Debbie repeated SDQ self-report scores. *Descriptors – very low, low, close to average, high, very high

Self-report raw scores								
	T1	Descriptor	T2	Descriptor	T3	Descriptor	T4	Descriptor
SDQ overall stress	10	Close to average	7	Close to average	12	Close to average	14	Close to average
Emotional distress	2	Close to average	2	Close to average	3	Close to average	4	Close to average
Behavioural difficulties	3	Close to average	1	Close to average	2	Close to average	4	Slightly raised
Hyperactivity and attentional difficulties	4	Close to average	3	Close to average	4	Close to average	4	Close to average
Difficulties getting along with other children	1	Close to average	1	Close to average	3	Slightly raised	2	Close to average
Kind and helpful behaviour	7	Close to average	7	Close to average	8	Close to average	9	Close to average

Table 8-14: Debbie repeated KIC self-report scores at T1, 2 and 4

Problems identified	T1	T2	T4
Concentrating	Yes	Yes	Yes
Getting tired easily	Yes	Yes	Yes
Remembering things	Yes	Yes	Yes
Keeping up with the rest of the class	Yes	No	No
Planning things, getting organized	No	No	No
Walking problems	No	No	Yes
Writing problems	No	No	No
Speaking or talking	No	No	Yes
Saying sentences so they make sense	Yes	Yes	Yes
Understanding what other people say	Yes	No	Yes
Reading	No	Yes	Yes
Feelings and behaviour	Yes	Yes	Yes

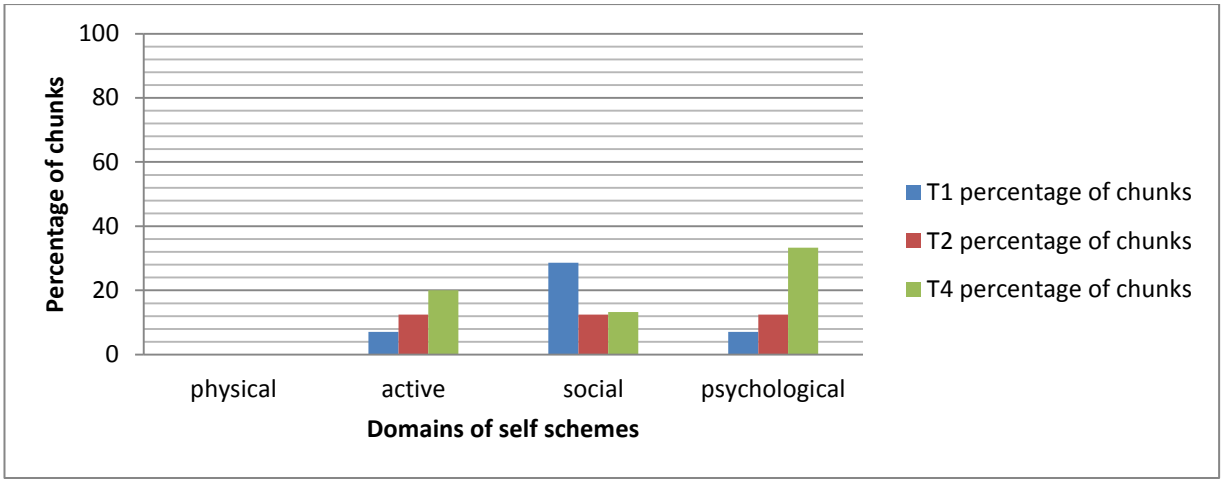

Figure 8-20: Debbie – percentage of SUI chunks data coded to each domain at T1, 2 and 4

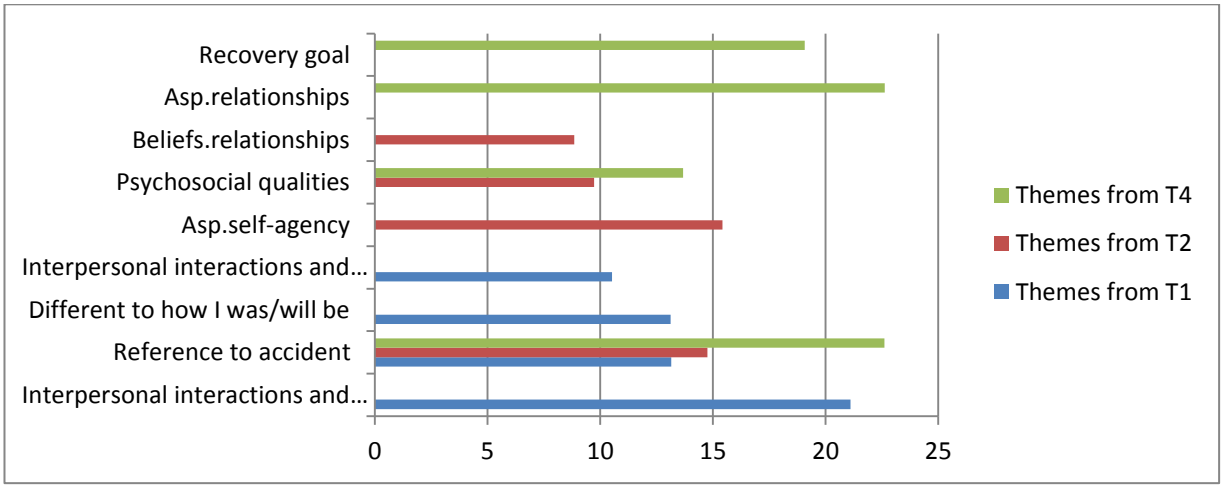

Figure 8-21: Debbie repeated SUI themes data at T1, 2 and 4

8.9 Stuart – 4 visits (13 years 10 months at injury; 17 years at recruitment)

All the research visits were carried out at home and arranged by Stuart's mother. Stuart studied 3 A levels and then left school during the research study. He was given a community "bravery" award and was involved in sports coaching with 5-6yr olds. He did work experience and then secured a sports coach apprenticeship locally. He had the same girlfriend throughout.

Stuart studied psychology and sociology and gave long involved answers in the interview and showed interest in the research project. His knowledge of the "incident", brain injury and its consequences increased over time.

The self-ratings of "social acceptance" and "physical appearance" both went down at T4 and were below the norm value. The only domain to reach the ceiling of 4.0 was job competence (see Figure 8-22).

Self-report of difficulties remained consistent across time. 8/12 items on KIC stayed the same over the four time points and in the SDQ self-report, "difficulties getting on with other children" remained **high** or **very high** and "kind and helpful behaviour" remained **very low** or **slightly low** (see Tables 8-15 and 8-16)

There was an increase in the scores of the Self-understanding interview. The scoreable chunks in the interview data reached a maximum level of 4.0 in all domains and the weighted mean increased from 3.0 to 3.9. Three of the themes at T4 had been expressed in other interviews (see Figure 8-24). A new theme of work was introduced and the overall interview had a forward looking quality that included aspirations and goals typical of his age.

> *I'll still be what I deem as funny, just see the funny side of everything. With any luck I'll still not have gone to a Jobseekers Allowance meeting and all of that. What might be different? Might be living with my girlfriend, I'll definitely have moved out but I might be living with my girlfriend. I'll have stayed levelheaded with any luck*

…Well I see my family have done their job now and whatever happens now is not their fault (Stuart, T4)

As much as I enjoy my high school friends and activities, I'm looking forward to leaving home and going to college, where I can be more independent, although I'm a little ambivalent. I love my parents, and really want to stay connected to them, plus, what they think about me is still really important to how I feel about myself as a person (Harter, late adolescence).

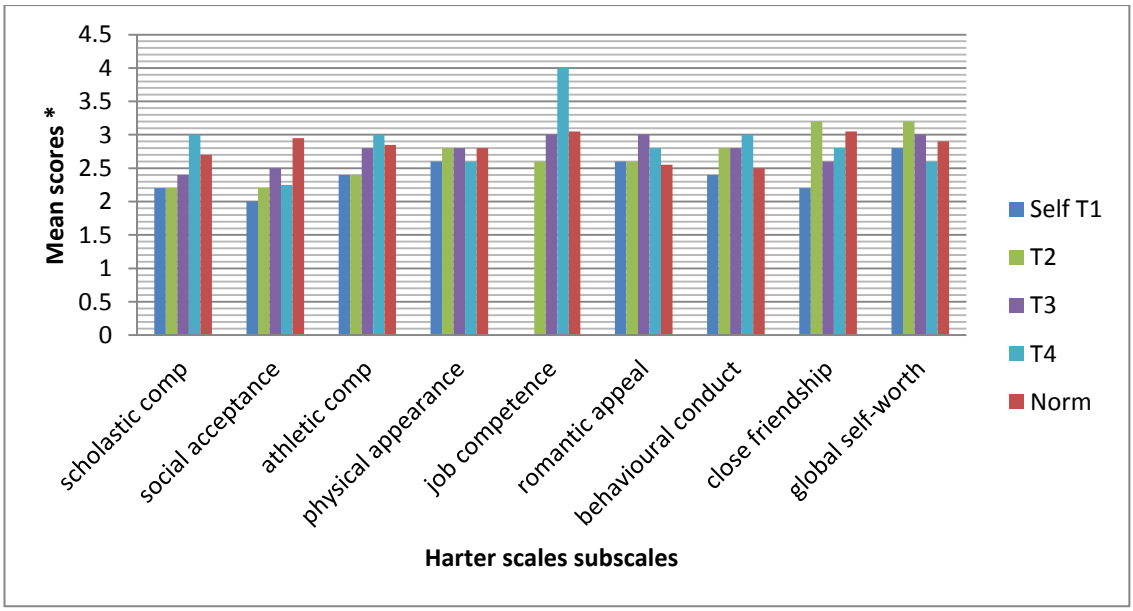

Figure 8-22: Stuart repeated Harter Scales self-report scores at T1, 2, 3 and 4. *mean scores range 1-4

Table 8-15: Stuart repeated SDQ self-report scores at T1, 2, 3 and 4

Self-report raw scores								
	T1	Descriptor*	T2	Descriptor	T3	Descriptor	T4	Descriptors
SDQ overall stress	14	Close to average	14	Close to average	14	Close to average	11	Close to average
Emotional distress	1	Close to average	0	Close to average	0	Close to average	0	Close to average
Behavioural difficulties	2	Close to average	4	Slightly raised	2	Close to average	1	Close to average
Hyperactivity and attentional difficulties	6	Slightly raised	6	Slightly raised	5	Close to average	5	Close to average
Difficulties getting along with other children	5	Very high	4	High	7	Very high	5	Very high
Kind and helpful behaviour	6	Slightly low	4	Very low	6	Slightly low	6	Slightly low

Table 8-16: Stuart repeated KIC self-report scores at T1, 2 and 4

Problems identified	T1 self-report	T2 self-report	T4 self-report
Concentrating	Yes	Yes	Yes
Getting tired easily	Yes	Yes	Yes
Remembering things	Yes	Yes	Yes
Keeping up with the rest of the class	Yes	Yes	No
Planning things, getting organized	Yes	Yes	Yes
Walking problems	No	Yes	No
Writing problems	Yes	Yes	Yes
Speaking or talking	No	No	No
Saying sentences so they make sense	No	No	No
Understanding what other people say	No	No	No
Reading	No	No	No
Feelings and behaviour	Yes	No	No

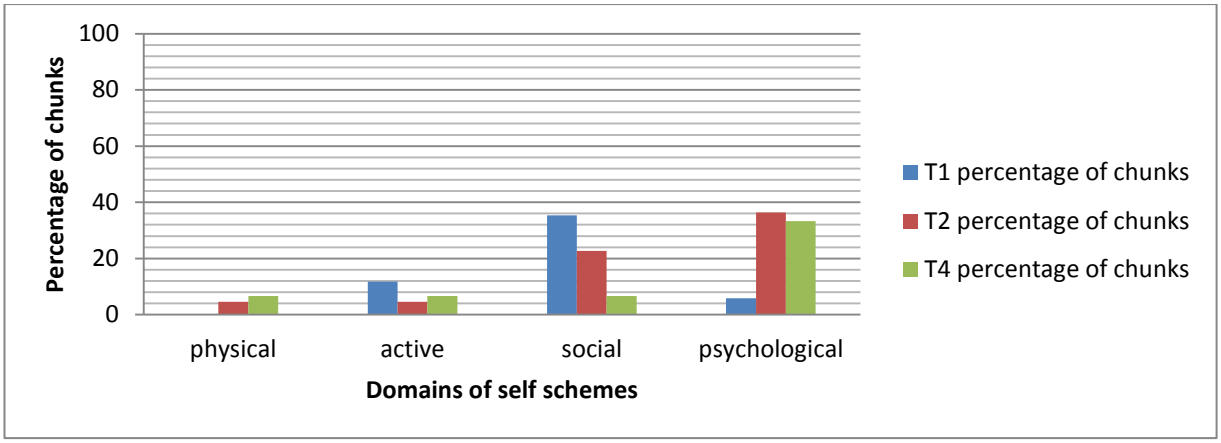

Figure 8-23: Stuart – percentage of SUI chunks coded to each domains at T1, 2 and 4

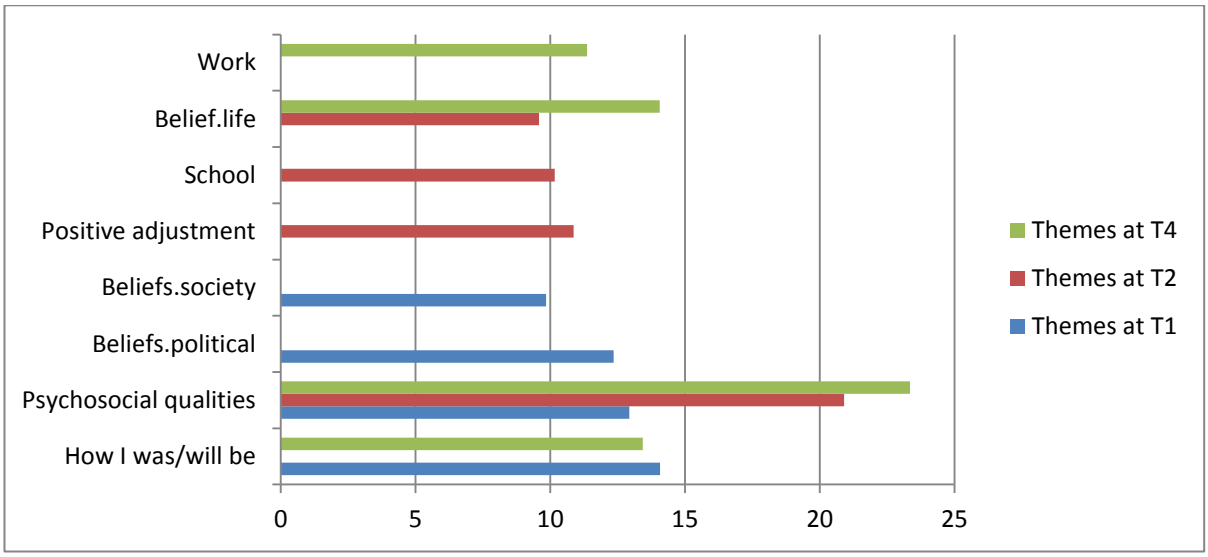

Figure 8-24: Stuart repeated SUI themes data at T1, 2 and 4

8.10 Rachel – 4 visits (14 years 6 months at injury; 16 years at recruitment)

Rachel moved house during the research project and had major building works in a new home in the same village. She had the same full time rehabilitation assistant throughout the research study, and then another one was added for weekends. Rachel became more sociable on visits, welcoming me at the door and offering me drinks etc. but on the final visit she became upset and did not want to continue with the data collection. She completed some of self-report questionnaire only (Harter). The rehabilitation assistant explained that she had some medication review and was now feeling a bit better, suggesting low mood.

Rachel continues to have little knowledge of her accident, recalling little of what she had been told. She had little knowledge of how the brain works and the consequences of an injury. Data is only available for T1,2 and 3 as Rachel did not complete data at T4.

At T3, five of the eight Harter items are scored above the norm value and close to the ceiling of 4.0 (see Figure 8-25). Self-rating of "difficulties getting on with other children" increased over time. At T3 it was scored as **very high** (see Table 8-17). The rating of "social competence" also fell to below the normative value. However, there was some inconsistency. The item "close friendship" was scored above the norm value at T3 (see Figure 8-25). Three of the eight items came close to the ceiling of 4.0 at T3 – "scholastic competence", "job competence" and "behavioural conduct". These items were all rated above the norm value.

The scoreable chunks of interview data showed a reduction of physical and active and an increase in psychological domain (see Figure 8-26). This is a pattern expected with increasing age. The chunks were also scored from 1-4. The weighted mean increased from 1.9 at T1 to 2.2 at T2 and the modal level increased from 1 to 2. These scores indicated that the responses were not so brief and concrete at T2 but they are still below the elaborate and abstract level expected at her age.

The themes in the interview data did not overlap between the interviews (see Figure 8-27). The themes of psychological qualities, relationships and aspirations about work are more reflective of her age. However, they were one-dimensional and simple and lacked the complex multidimensional conflict that would typically be seen in middle adolescence:

> *Because I heard that family's the most important thing in life and so I started to believe it and it came true for me (T2)*

> …so I'm very responsible at work, which makes me feel good about myself there. But then I go out with my friends and I get pretty crazy and irresponsible. So which am I, responsible or irresponsible? How can the same person be both? If my parents knew how immature I act sometimes, they would ground me forever, particularly my father. I'm real distant with him. I'm pretty close to my mother though. (Harter, middle adolescence)

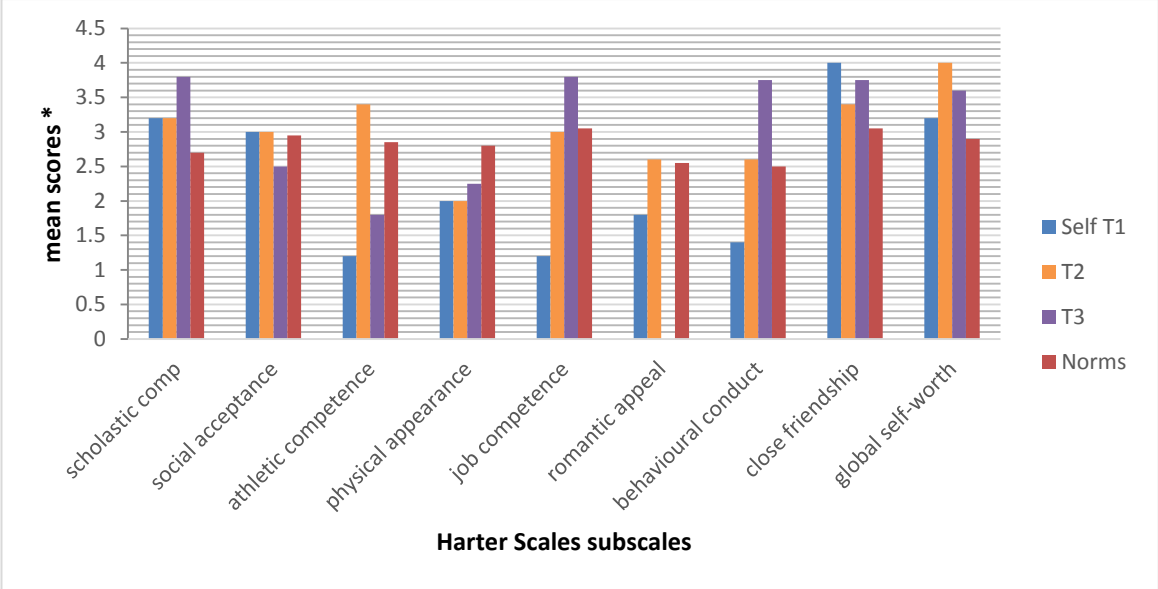

Figure 8-25: Rachel repeated Harter Scales self-report scores at T1, 2 and 3. *Mean scores range 1-4

Table 8-17: Rachel repeated SDQ self-report scores at T1, 2 and 3. *Descriptors – very low, low, close to average, high, very high

Self-report raw data						
	T1	Descriptor *	T2	Descriptor	T3	Descriptor
SDQ overall stress	8	Close to average	11	Close to average	11	Close to average
Emotional distress	1	Close to average	3	Close to average	3	Close to average
Behavioural difficulties	4	Slightly raised	2	Close to average	1	Close to average
Hyperactivity and attentional difficulties	3	Close to average	3	Close to average	1	Close to average
Difficulties getting along with other children	0	Close to average	3	Slightly raised	6	Very high
Kind and helpful behaviour	5	Low	9	Close to average	10	Close to average

Table 8-18: Rachel repeated KIC self-report scores at T1 and 2

Problems identified	T1 self-report	T2 self-report
Concentrating	Yes	Bit
Getting tired easily	No	No
Remembering things	Yes	Bit
Keeping up with the rest of the class	Yes	No
Planning things, getting organized	No	No
Walking problems	No	No
Writing problems	No	No
Speaking or talking	No	No
Saying sentences so they make sense	No	No
Understanding what other people say	Yes	No
Reading	No	No
Feelings and behaviour	Yes	No, none of that

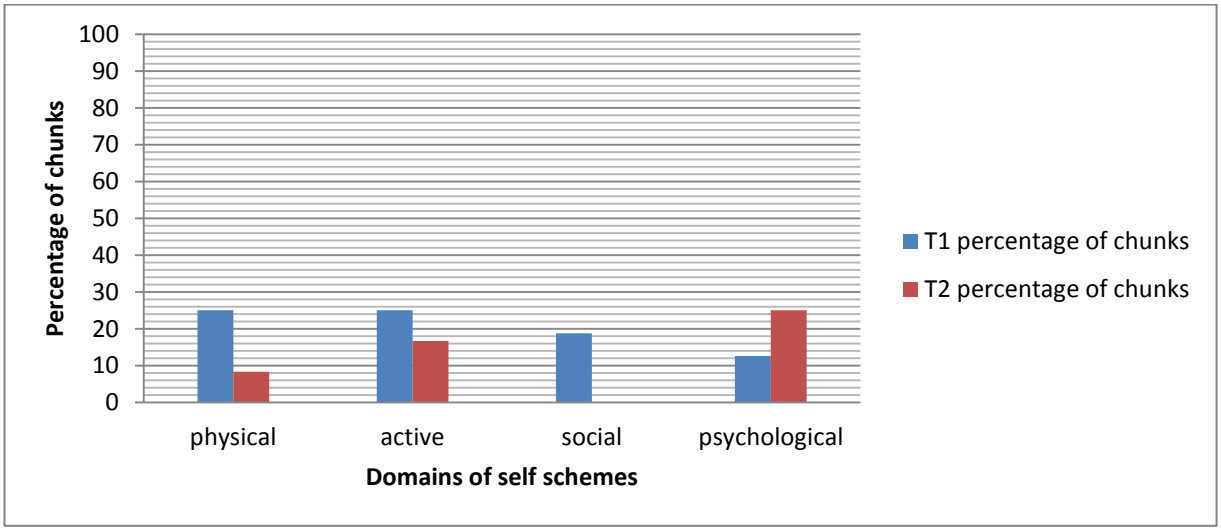

Figure 8-26: Rachel – percentage of SUI chunks coded to each of the domains at T1 and 2

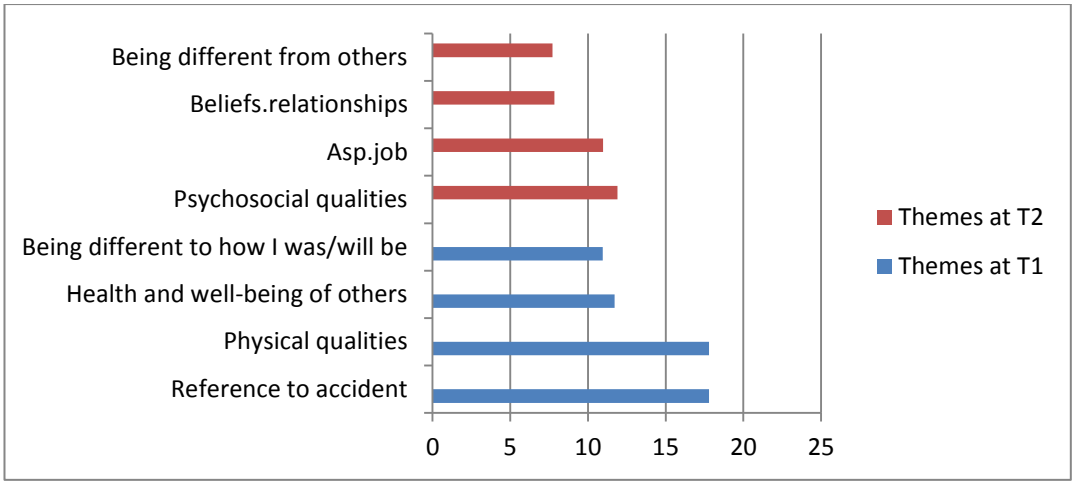

Figure 8-27: Rachel repeated SUI themes data at T1 and 2

8.11 Dan – 4 visits (9 years 6 months at injury; 10 years at recruitment)

Dan remained at the same home and school and he got a new dog. His Dad and girlfriend moved to a new home. His physical skills increased and he no longer needed a wheelchair and started to ride a bike again.

Dan was more able to contribute to the research process over time and was able to engage in the interview and self-rating measures.

The self-report data in the Harter scales had a changeable profile. At the final data collection point, all domains were rated below norm (see Figure 8-28).

Dan recognised a different profile of deficits in the KIC across time. He reported the same number of items of difficulty but at the later interview he was more aware of cognitive, emotional and behavioural difficulties (see Table 8-19). There is a change in the interview data across time with the emergence of some items in the psychological domains such as would be expected with increasing age, but a reduction in the physical domain would have also been expected (see Figure 8-29).

The scoreable chunks consistently scored at 1 across time. A greater score would have been expected at his age.

The interviews included more data over time and different themes emerged (see Figure 8-30). The data started to include some of the comparative themes that would be expected at this age ie "different from how I was/will be" and "being different from others" but were more simple than expected:

> *Cos I'm loopy and they ain't loopy. There is someone like me…well I want to be like him*
>
> Who?
>
> *Elvis Presley (T4)*
>
> But I'm feeling pretty dumb in Math and Science, especially when I see how well a lot of the other kids are doing. Even though I'm not doing well in those subjects, I still like myself as a person, because Math and Science just aren't that important to me (Harter, middle to late childhood).

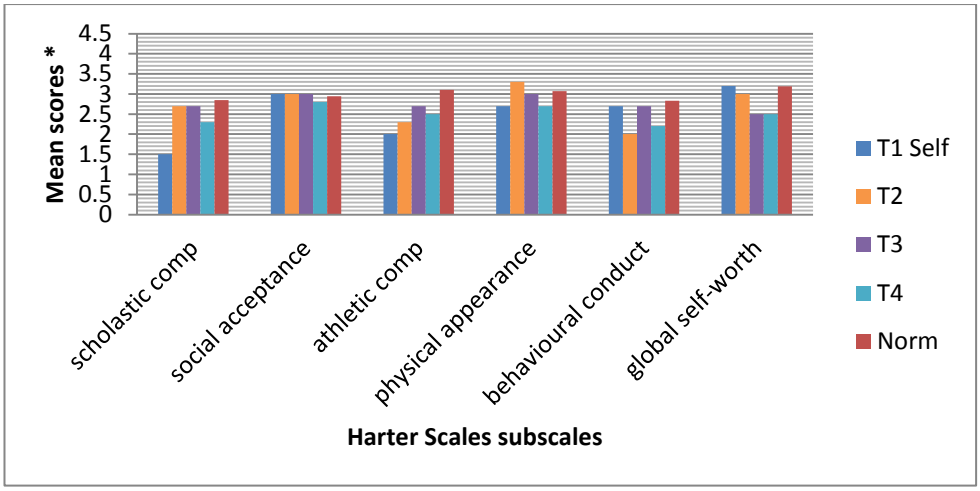

Figure 8-28: Dan repeated Harter Scales self-report scores at T1, 2, 3 and 4. *Mean scores range 1-4

Table 8-19: Dan repeated KIC self-rating scores at T1, 2 and 4

Problems identified	T1	T2	T4
Concentrating	Unable to complete T1	No	Yes
Getting tired easily		Yes	No
Remembering things		Yes	Yes
Keeping up with the rest of the class		Yes	No
Planning things, getting organized		No	No
Walking problems		No	No
Writing problems		No	No
Speaking or talking		Yes	Yes
Saying sentences so they make sense		No	Yes
Understanding what other people say		Yes	Yes
Reading		Yes	No
Feelings and behaviour		I don't know	Yes

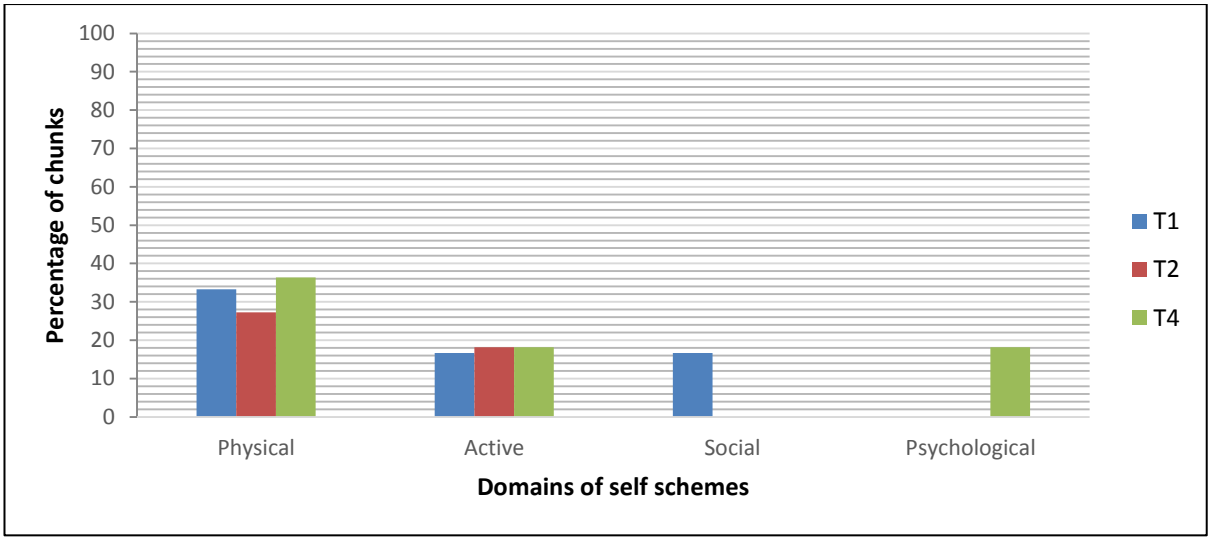

Figure 8-29: Dan – percentage of SUI chunks coded to each of the domains at T1, 2 and 4

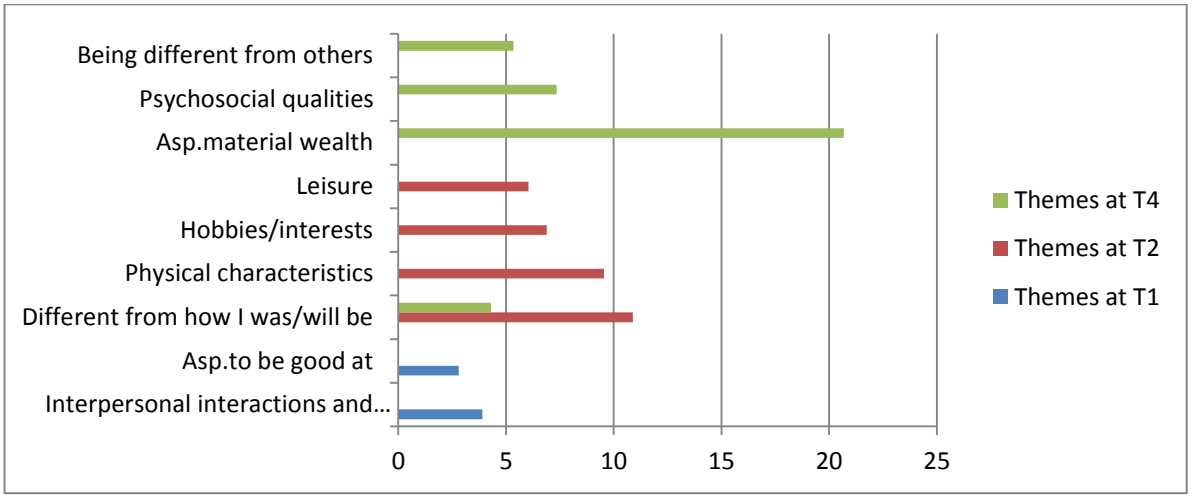

Figure 8-30: Dan repeated SUI themes data at T1, 2 and 4

8.12 Summary

This chapter has presented the data over time to explore the third and fourth research questions.

3. *Explore the profile of the ongoing development of self-awareness following TBI in childhood*

4. *Compare the ongoing profile to typically developing children as reported in the literature*

Ten children and young people remained in the study until the third and fourth visits to provide these longitudinal data. It was possible to detect change in the profile of the children and young people in two ways. First, there were changes in the raw scores, and where available the mean scores. Second, it was possible to look at the available normative data and therefore, compare to that expected in typically developing children.

All of the participants had some positive changes in scores in at least one measure. Some of the scores reached the maximum in the Harter Scales and some of the participants had interview data that were similar to their age-matched peers.

In the next chapter the patterns across the cases will be presented. In order to integrate the data and explore the common themes, the comparison data presented in Chapter 6 and the change over time presented in this chapter will be used.

9 Chapter 9: Results of cross-case analysis

9.1 Introduction

The previous chapters have reported the results for individual cases. The levels of discrepancy were summarised for each child/young person in each domain and supporting data was presented. Each case had a summary data display and this formed a framework to begin the process of across case analysis.

This chapter will present the patterns across the results of the fifteen cases, and also by domains. Following this, further analysis will be presented of the patterns in the data from each measure and the characteristics will be reviewed to match the patterns to other variables. So for each measure, the questions may be which children and young people had high/low scores and did they have other factors in common such as age? A further section will describe the common themes from the thematic analysis for all cases. Finally the cross-case analysis will consider the data in relation to age at injury, time since injury and change over time.

Reference will be made to individual participants throughout this chapter and a table of age characteristics is presented in the table below as a reminder, and a convenient reference for this chapter.

Table 9-1 Injury characteristics of participants in age order (youngest to oldest at injury)

	Age at injury (years)	*Time since injury (years)*
William	5.9	3.5
Rosie	8.6	4.8
Dan	9.5	1.2
Henry	10.1	3.8
Peter	11.8	3.3
Kevin	12.9	4.6
Robert	13.2	4.6
Stuart	13.8	4.0
Rachel	14.5	1.7
Tracey	14.9	3.7
Rupert	16.4	2.0
Amelia	16.4	2.7
Dale	16.8	1.7
Debbie	17.0	1.6
Lee	17.1	1.7

9.2 Cross-case analysis of profiles

As described previously, individual summative profiles of the merged data were used to create visual data displays – see Chapter 6. The data were assigned to one of seven domains - physical, cognitive, emotional/psychological, social, behavioural, communication and school/learning, and the level of discrepancy was calculated. The levels of discrepancy were displayed in a 'red, amber, green' colour scheme. Red represented discrepancy and green represented agreement in the data between the self-report and the others report and also between the normative data or trends. Amber was used when there was both agreement and discrepancy in the same domain e.g. between measures. Both the self-others discrepancy and the self-norm discrepancy were displayed visually. The visual data displays were

very useful. It was straightforward to look at the displays and see that the colour scheme indicated the level of discrepancy in each of the domains for each of the cases.

9.2.1 Self-other discrepancy

Within the self-others discrepancy, one child had "discrepancy" across all of the domains (Dan). None of the children/young people had agreement across all of the domains (see Figure 9-1). There was one case where all the domains had some agreement (Rupert). Dale had the greatest amount of agreement (3 domains) in the self-others data.

The domains with the greatest amount of self-others discrepancy were **Social** and **Behavioural** (see Figure 9-3). None of the children/young people had agreement in the behaviour domain and nine cases had discrepancy in the social domain. The domain with the greatest amount of self-others agreement was **Communication**

This result indicated that the children and young people were able to recognise their communication difficulties more readily, and were less able to recognise their social and behavioural difficulties.

9.2.2 Self-norm discrepancy

Dale also had the greatest number of domains of agreement (3) in the self-norm discrepancy (see Figure 9-2). Rachel had the most discrepancy (3 domains).

The same four cases (William, Dan, Rachel and Rosie) had the greatest number of domains of discrepancy in both self-others and self-norm discrepancy (see Figures 9-1 and 9-2).

The pattern of discrepancy across domains in the self-norm discrepancy was different from that reported above i.e. self-others discrepancy. The domains with the greatest amount of self-norm discrepancy were **School/learning** and **Physical** while the domain with the greatest amount of agreement was **Cognitive** (see Figures 9-4).

This result indicated that the self-report of the children and young people were more closely aligned to the normative scores in the cognitive domains and less typical in the school and physical domains.

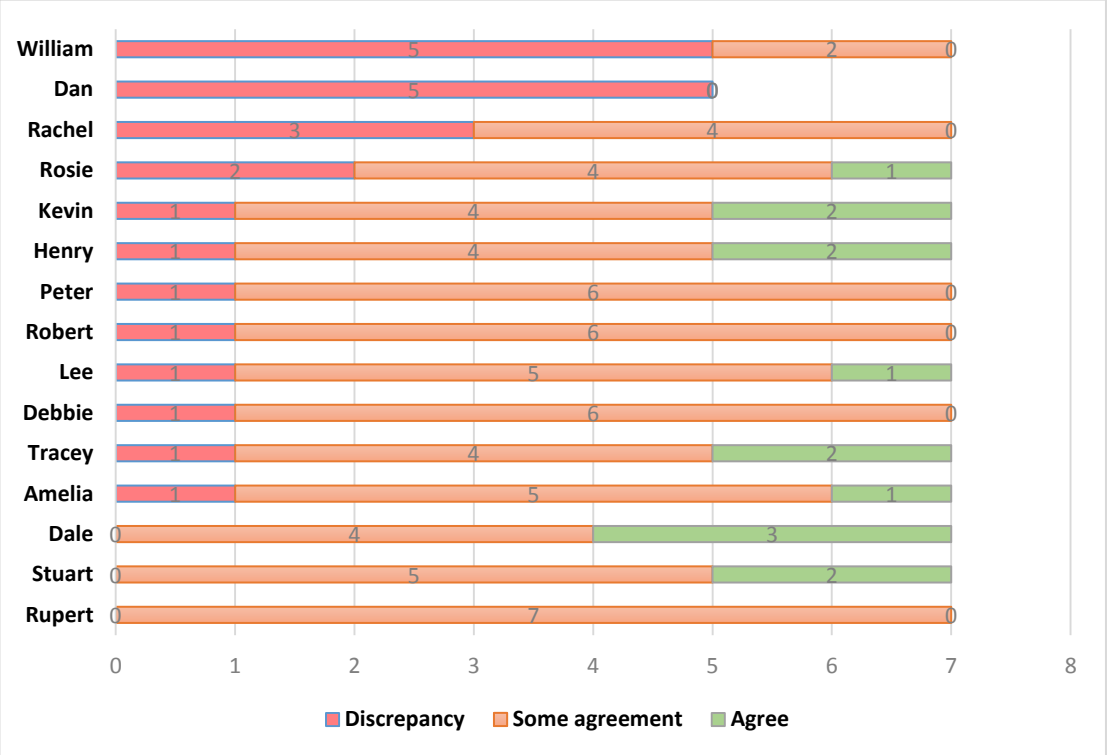

Figure 9-1: Frequency of self-others discrepancy by case

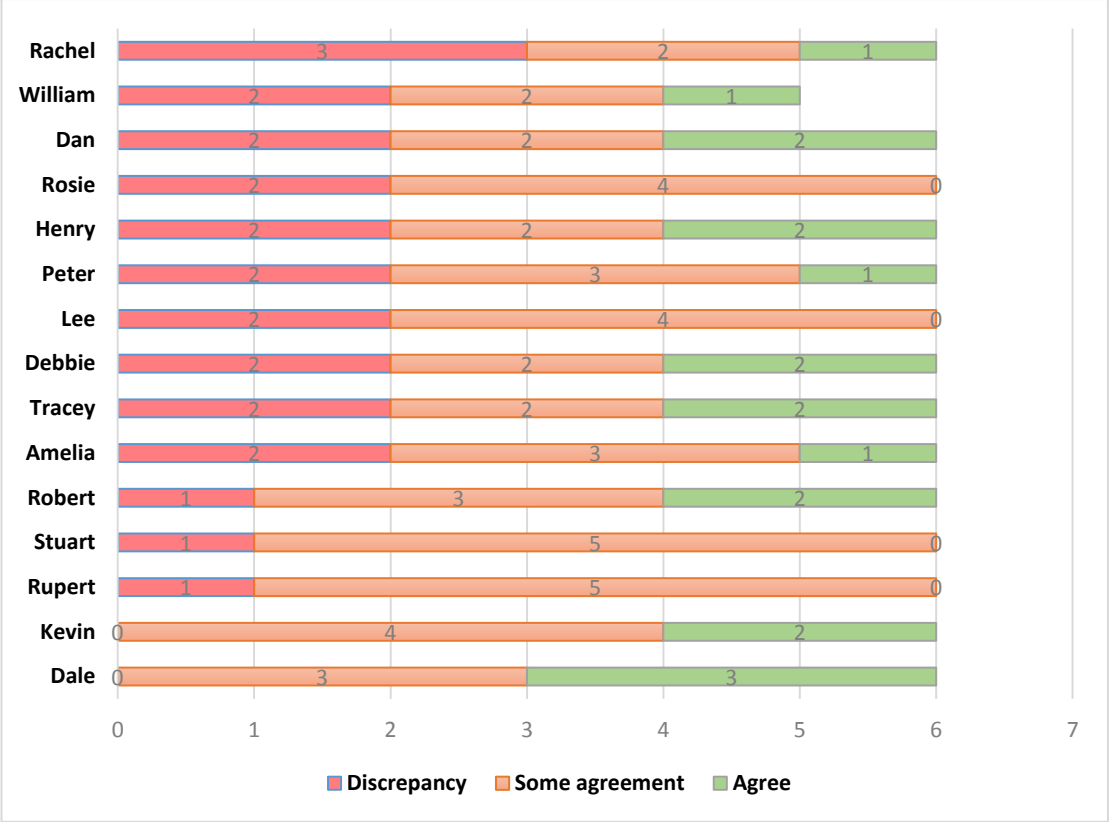

Figure 9-2: Frequency of self-norm discrepancy by case

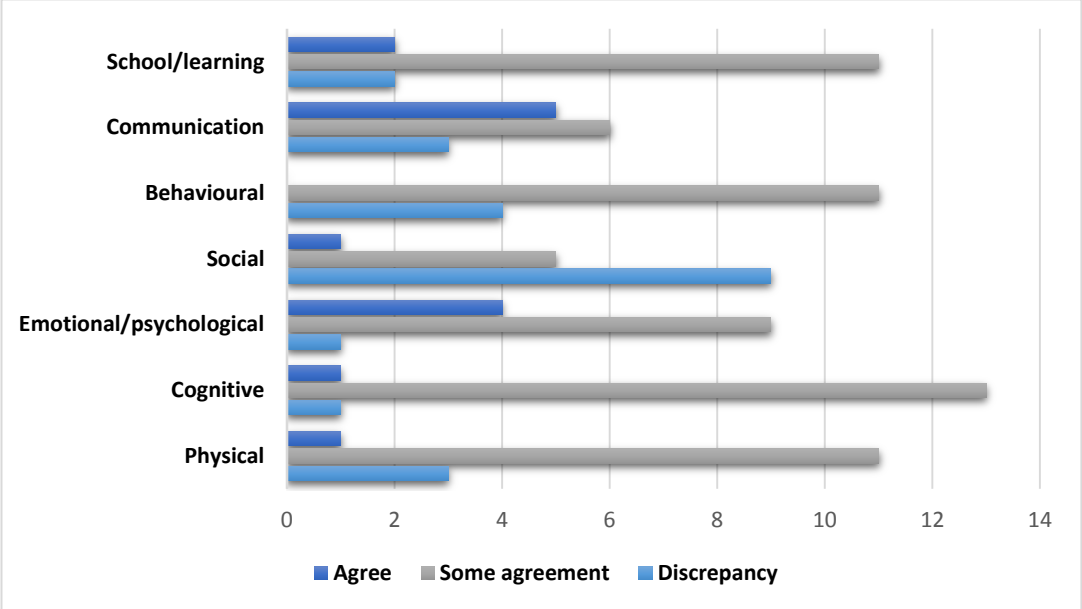

Figure 9-3: Frequency of self-others discrepancy by domain

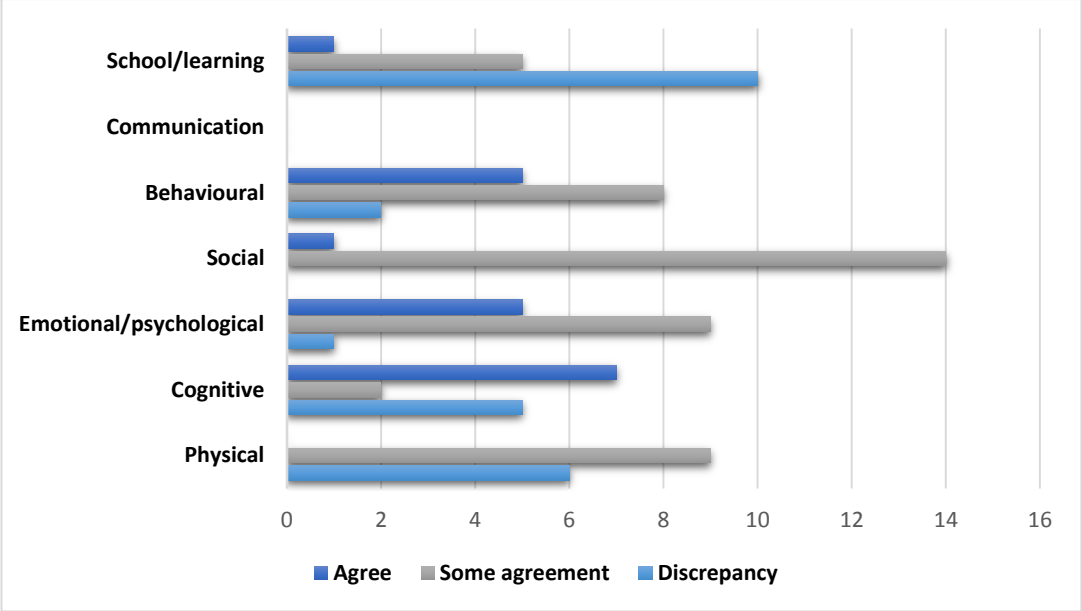

Figure 9-4: Frequency of self-norm discrepancy by domain

Having established the broad patterns in the data across the cases and across the domains, some more detailed exploration was carried out. Patterns within the data for each measure were explored.

9.3 Cross-case analysis by measures

9.3.1 Harter Scales of Perceived Competence

The maximum rating in this measure is 4.0. Although many of the young people were at the upper end of the age-range for this assessment, no children/young people reached the ceiling of the items "scholastic competence" or "romantic appeal". In contrast, five cases reached the ceiling for their self-report of the item "close friendship".

The self-rating scores at T1 were below the age expected levels on some of the items in all of the cases. From the cases where there were few items below the norm, Dale rated below the norm value only for the item "job competence" and Henry rated below the normative value only for the item "romantic appeal". Henry reached the maximum score of 4.0 in five items.

In contrast there were many cases with a number of items below the norm. Stuart rated below norm for 8/9 items and Lee rated below norm for 7/9 items (see Figure 9-5). For the remaining items that they scored, they both rated above norm for the item "romantic appeal".

The children and young people who had similar test scores, did not share any injury or personal characteristics.

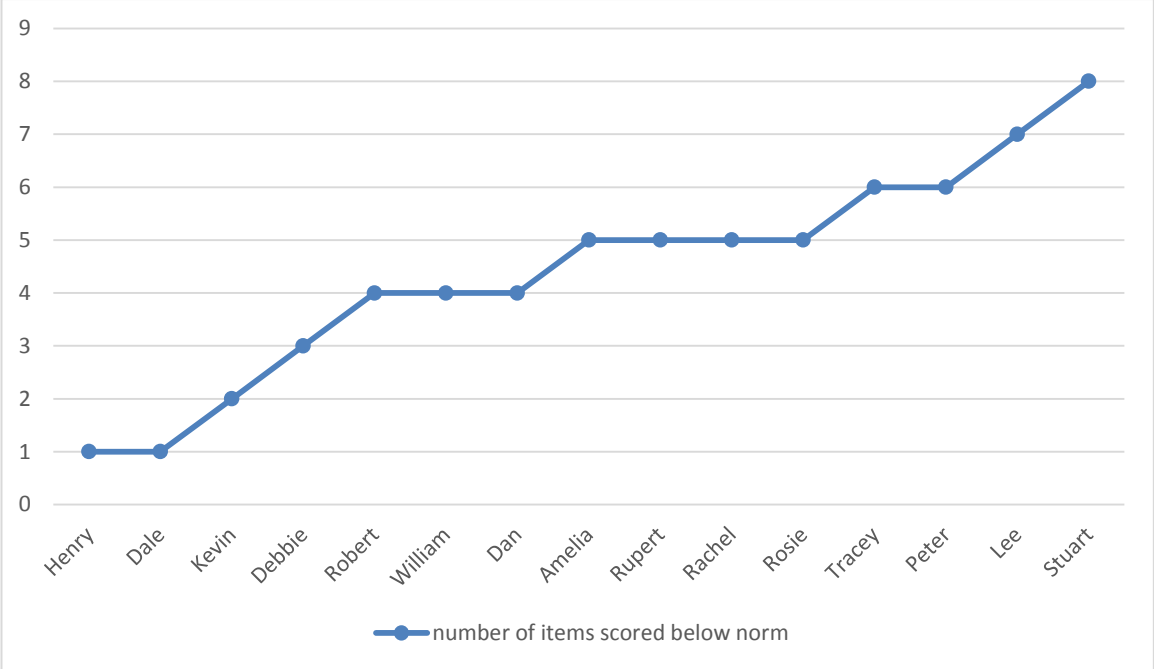

Figure 9-5: Number of items each child/young person rated below the norm (Harter Scales)

The most commonly reported items where the self-report was below the norm were scholastic/job competence, physical appearance and athletic competence. The social acceptance item was most commonly reported as above the norm value by the children/young people (see Figure 9-6). Collectively, the social and behavioural items were the ones where the children and young people more often rated themselves above the norm (Figure 9-6). Interestingly, social and behaviour were the domains that had the most overall self-other discrepancy in the profile results above.

As previously explained, self-others discrepancy and self-norm discrepancy scores are generated. There is one item in the Harter Scales, athletic competence, which generated interesting results. Although, as seen above, the self-report was below that expected in the norms in the athletic competence item, it was also the item where the scores were most discrepant from that of the teacher. Nine of the

thirteen children and young people over-rated their performance compared to the teacher report. So they recognised that their performance was below that of the norms, but still overated their performance compared to the teacher report. Further discussion of what constitutes a discrepancy will take place in the discussion chapter.

Scholastic competence was the item that the children and young people most often rated themselves lower than the teacher – 8/13 cases. There was some missing teacher data for comparison.

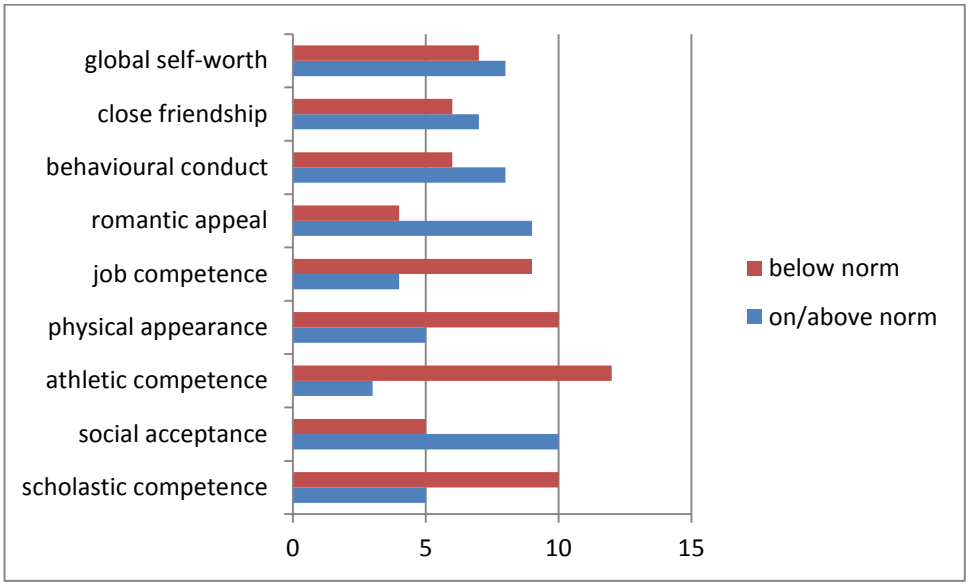

Figure 9-6: Frequency of self-rating compared to norm values

9.3.2 Knowledge Interview for Children

The final section of the KIC provided the most data concerning discrepancy as it addressed the child/young person's report of their own difficulties following their injury. An open question "How about you, do you have any problems since your accident?" was posed first. Two children/young people did not provide an answer. Three young people gave a simple yes/no answer. Six children/young people

mentioned one domain (motor n=2; cognitive, socialising, psychological, anger n=1) and only one young person gave a full and elaborate response. The second question was more specific "Now I'm going to list some of the problems people say they have – I want you to tell me if any of these are true for you" and the children/young people were able to engage fully, sometimes giving long answers.

The most commonly self-reported difficulties were "getting tired easily" and "concentrating" (see Figure 9-7). Tracey described that fatigue is not just about physical tiredness

> *If I do something that takes a lot of concentration I notice that I will, like my concentration levels and my tiredness will go like if I have to concentrate and do something quite big, like of my brain has to take on something quite like academic or something like that I will get tired (Tracey T2)*

Amelia's parent report also describes the impact of fatigue on her everyday interactions

> *This has improved enormously but certain activities can cause ** to get tired easily, such as meeting groups of people with a lot of conversation (Amelia's parent T1)*

The items that were reported the least were reading, writing, walking and planning/getting organised. Although the children and young people did not identify the difficulties in planning/organising, the parents seemed more aware of them. Consequently this item caused the greatest discrepency in the self-other report (see Figure 9-8).

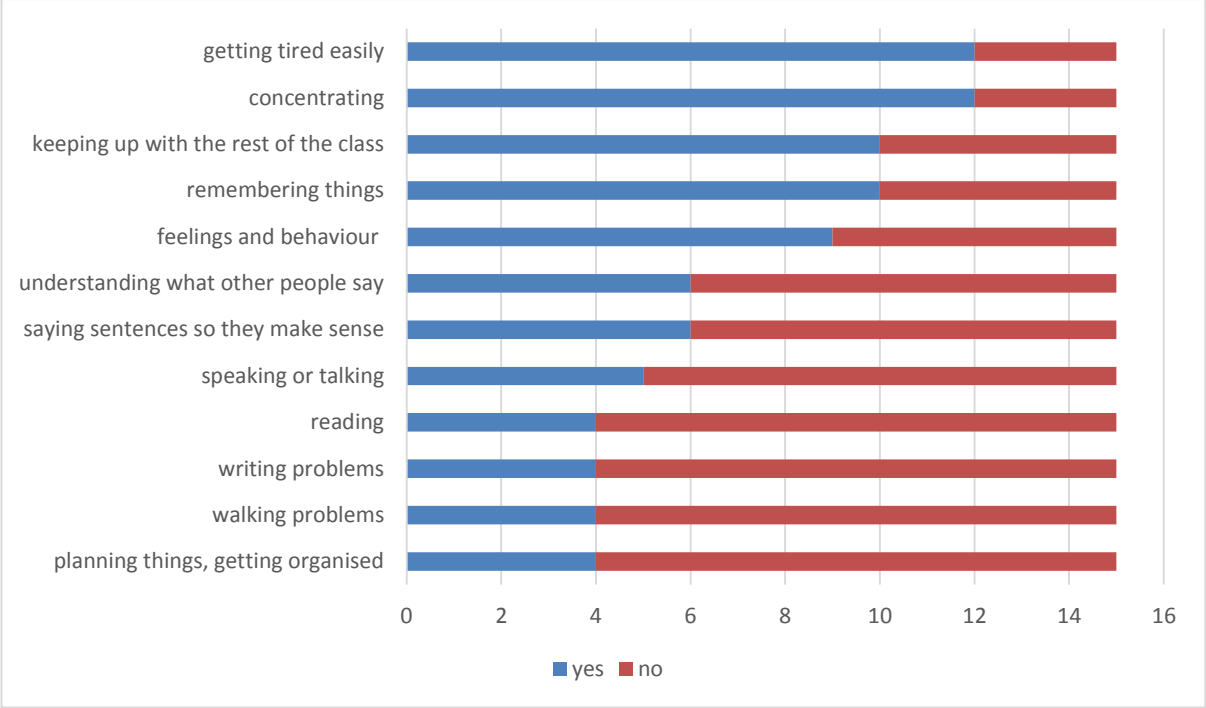

Figure 9-7: Frequency of self-reported difficulties at T1 (KIC)

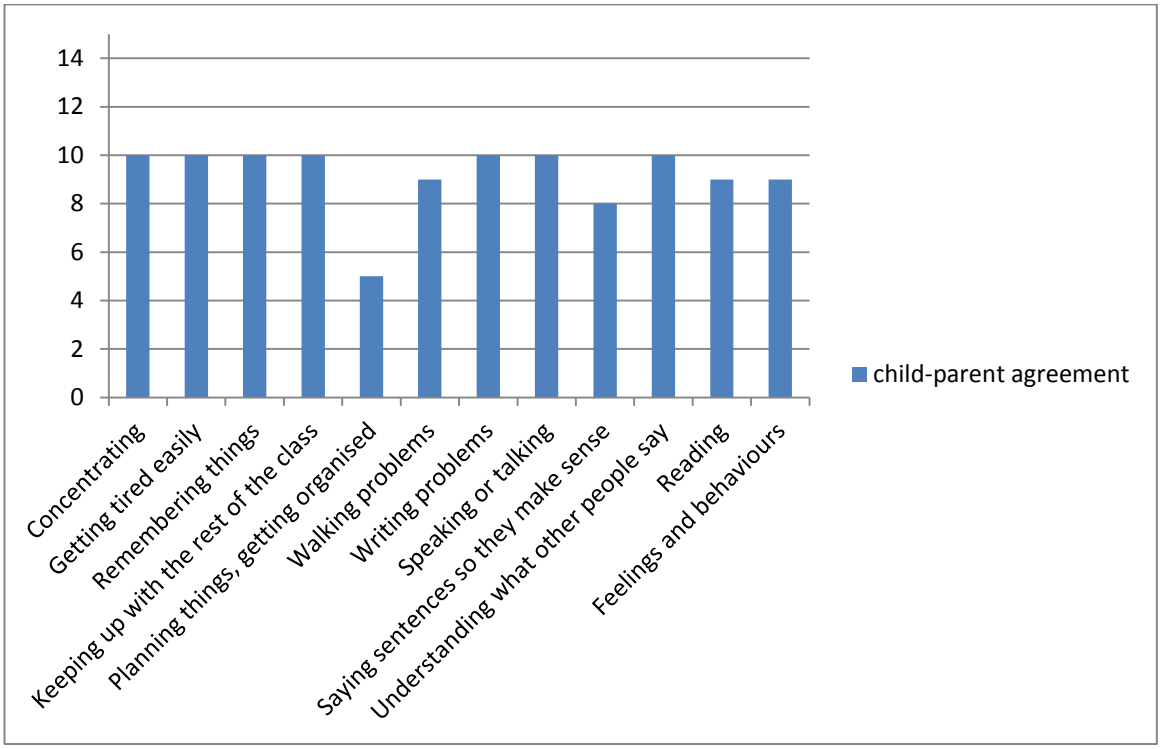

Figure 9-8: Number of cases with child-parent agreement (KIC)

The Awareness Discrepancy Index was derived from the number of difficulties that were included in the parent report that were not endorsed by child/young person. The maximum was 12. A higher score indicated less awareness of difficulties. William and Rachel had the highest scores (8 and 7 respectively) while Henry and Lee had a score of 0. William, Rachel and Lee all had a GCS score of six, but did not share other age or injury characteristics.

Lee identified all 12 areas of difficulty and these were all endorsed by parent report, whereas Henry's scores were somewhat different. In his case, Henry identified more items than his parent. There were three items of self-reported difficulty but none of them were endorsed by parent report.

There were seven other cases that included items in the self-report that were not endorsed by the parent report. The most common item was "keeping up with the rest of the class". The children and young people seemed more able to identify their classroom difficulties and this is similar to the previous finding that they commonly rated their scholastic competence below the norm in the Harter Scales self-report.

9.3.3 Strengths and Difficulties Questionnaire

The SDQ was completed by 13 of the children and young people at T1. Two of the children were too young to complete the self-report version. The young people with the greatest self-parent discrepancy were Debbie, Rachel, Tracey, Dale and Rosie. Overall, there is a greater amount of disagreement than agreement between

the self-report and the parent in this measure. The item with least agreement was "kind and helpful behaviour" (see Figure 9-9).

The composite "overall stress" values were **close to average** in 11/13 cases and only **slightly raised** in the others. Rachel and Kevin had the lowest "overall stress" scores and Lee, Stuart, Rosie and Peter had the highest "overall stress" score. These four young people were among the ones who had the highest number of self-report items below the norm in the Harter Scales (see Figure 9-5 and Table 9-1).

There were four cases where the self-report of "hyperactivity and attentional difficulties" was below the average range - Rupert, Robert, Stuart, Rosie. These young people also identified "concentration" as an area of difficulty on the KIC item. As with the KIC, examination of the discrepancy scores revealed that in four out of the five items there were cases where the child/young person reported more difficulty than their parents.

Table 9-2: "overall stress" scores. Smaller score = less stress (SDQ)

SDQ Overall Stress	T1 score	Descriptor
Rachel	8	close to average
Kevin	8	close to average
Rupert	10	close to average
Debbie	10	close to average
Robert	11	close to average
Tracey	11	close to average
Dale	11	close to average
Amelia	12	close to average
Henry	12	close to average
Lee	14	close to average
Stuart	14	close to average
Rosie	15	slightly raised
Peter	16	slightly raised

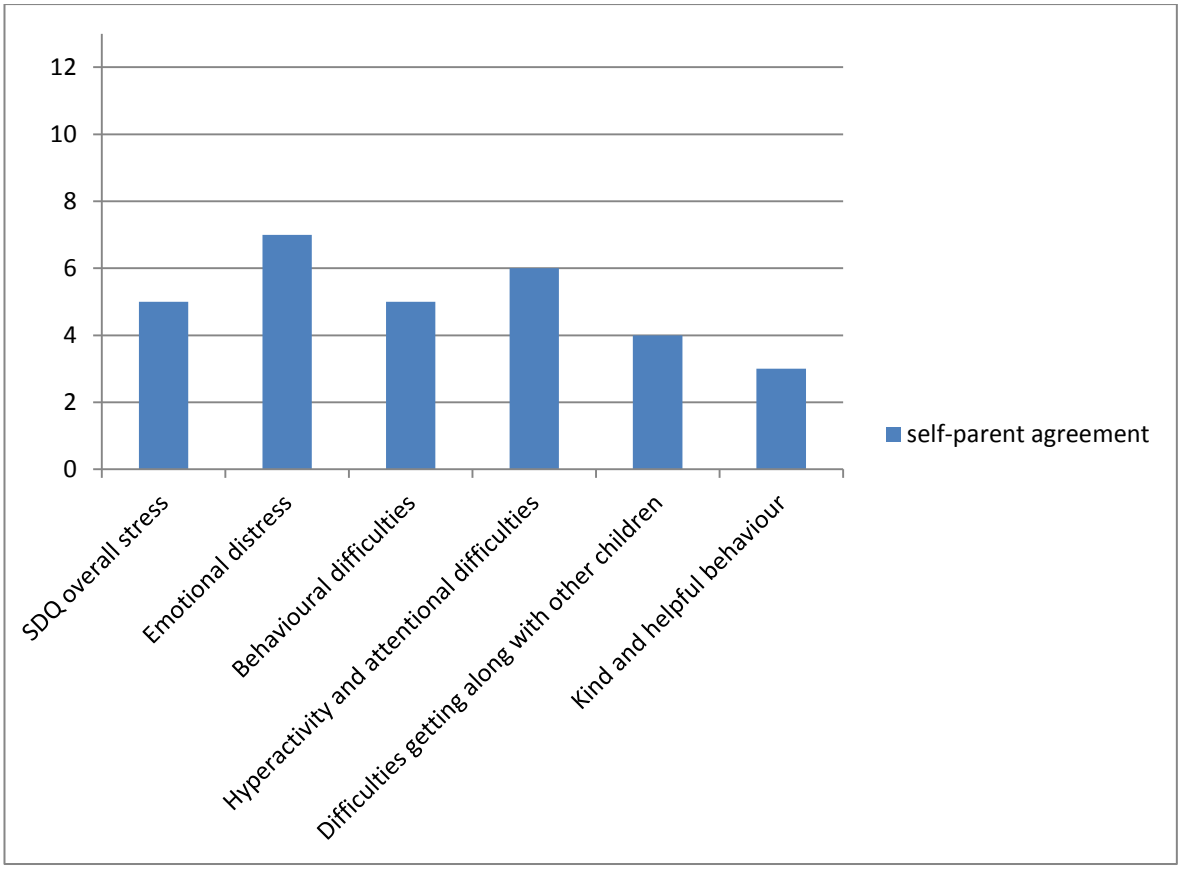

Figure 9-9: Number of cases with self-parent agreement (SDQ)

9.3.4 **Self-Understanding Interview**

The interview transcript data were quantitized using the scoring system developed by the authors (Damon and Hart, 1988). The numerical data could be compared to normative trends. The ceiling for the scoreable chunks was 4.0. Two cases reached a modal level of 4.0 at T1 (Stuart and Rosie) and eight cases only reached the lowest modal level of 1.0. This lower level is assigned to narrative that is concrete in nature and does not contain elaborated responses. Additionally there is a lack of values and future goals.

These data demonstrated that many of the children and young people had difficulty describing themselves at an age appropriate level.

9.3.5 **Cooking task**

Ten children and young people were presented with the Cooking Task and the Executive Function Map to rate their before and after performance. In one case the young man declined the task as it looked too difficult. In all cases there was a change in self-rating before and after the task. In seven of the cases the self-rating increased but in two of the cases the self-rating after was lower than before. In one of these cases the score afterwards was more closely aligned to the researcher score and the other case became more discrepant.

There was only one case where the researcher and the young person agreed (Stuart). In two cases the researcher rating was higher than the self-rating and in the other six cases the self-rating was higher (see Figure 9-10). The two cases where there was the closest agreement were Stuart and Debbie. The cases with the greatest amount of discrepancy were Amelia, Lee and Rachel.

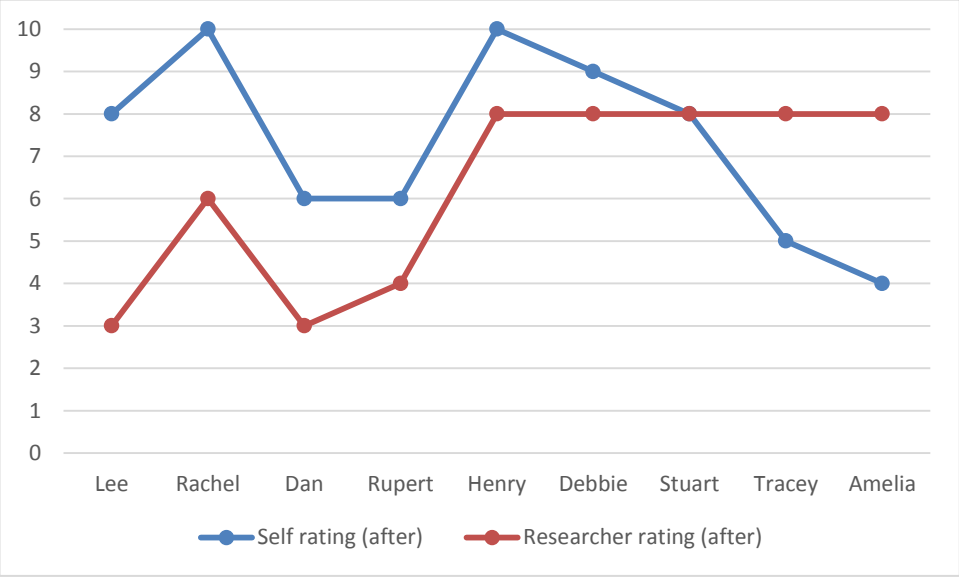

Figure 9-10: Self-rating and researcher rating of Cooking Task

As it is a new measure, the Cooking Task only has a small amount of norm data from a pilot study. The maximum number of errors in the pilot sample of typically developing children was 34 (Chevignard et al., 2009). Five out of the nine children and young people who completed the Cooking Task in this task also had total error scores below 30 (see Table 9-2). The maximum number of errors was 75 (Lee). One young person anticipated correctly that the task would be difficult for him and chose not to attempt it (Robert).

The most common error was commentary – question. This was defined as:

> *any question, remark or joke to the examiners, although the subject had been clearly instructed to act as if he/she were alone, such as commenting on the weather, or asking how to perform an action, or where to find an ingredient or a utensil (Chevignard et al., 2009).*

Although the commentary – question error was the most common, there was a wide range of frequency of this type of error score. In addition, there was a sex difference. The girls in the study had a low frequency in this type of error with a maximum of three.

Table 9-3: Number of error scores on Cooking Task

Cooking	Omissions	Additions	Substitution-sequence errors	Estimation errors	Commentary - questions	Total
Lee	4	7	11	11	42	75
Dan	7	5	9	10	19	50
Rupert	6	4	4	4	27	45
Rachel	1	12	6	9	2	30
Stuart	0	5	1	6	17	29
Debbie	4	0	12	12	0	28
Henry	2	6	4	3	11	26
Tracey	1	1	0	10	3	15
Amelia	0	1	7	1	3	12
Total	25	41	54	66	124	

9.4 Cross-case analysis of themes

The thematic analysis of the SUI narrative transcripts of individual cases was presented in Chapter 7. The quantitized data was reported above and this section will outline some cross-case analysis of themes.

There were 32 interviews altogether from the three research visits (T1, T2 and T4). The themes were compared across all of the interviews and the most common themes are reported here. The five most common themes were:

- Psychosocial qualities
- Being different (to how I was /will be)
- Reference to accident

- Physical characteristics
- Being different (from others)

These five themes were coded to more than 20 of the interviews. They were referenced between 58 and 153 times across all of the interview data by at least 13 cases (see Table 9-3).

The most common theme of psychosocial qualities was similar to typically developing children especially those in teenage years.

> *I know that my brain is what controls my personality and that it will be the same even if I do take on different opinions; it will always be me because it's my brain (Tracey)*

> *In year 11 I was always sort of very very quiet. Whereas in sixth form, I'm a little bit louder, I'm not too loud (Stuart)*

Table 9-4: Frequency of most common themes across SUI interviews

	Number of interviews (n=32)	**Number of cases (n=15)**	**Number of References**
Psychosocial qualities	31	14	153
Being different (to how I was /will be)	30	15	109
Reference to accident	23	13	84
Physical characteristics	24	13	71
Being different (from others)	29	14	58

The relationship between these themes was examined further. The results of a coding query from N-Vivo demonstrated a link between the themes of "brain injury" and "being different" (see Figure 9-11). The children/young people felt that it was in the context of their brain injury that they perceived themselves as being different from others and being different from themselves:

> *I'll be going back to the old me (Rachel)*
>
> *Will you be the same or different in 5 years? Different hope so (laugh). But hopefully next year like I have, I'll have like circumstances and all that helping me out more (Debbie)*
>
> *Cos no one's had the brain injury like me cos brain injury's one thing you can't be the same as, every brain injury's different (Rupert)*
>
> *My brain injury makes me different from everyone else. My brain injury defines who I am now and no one will have an identical brain injury to me in the world. So that makes me unique (Tracey)*

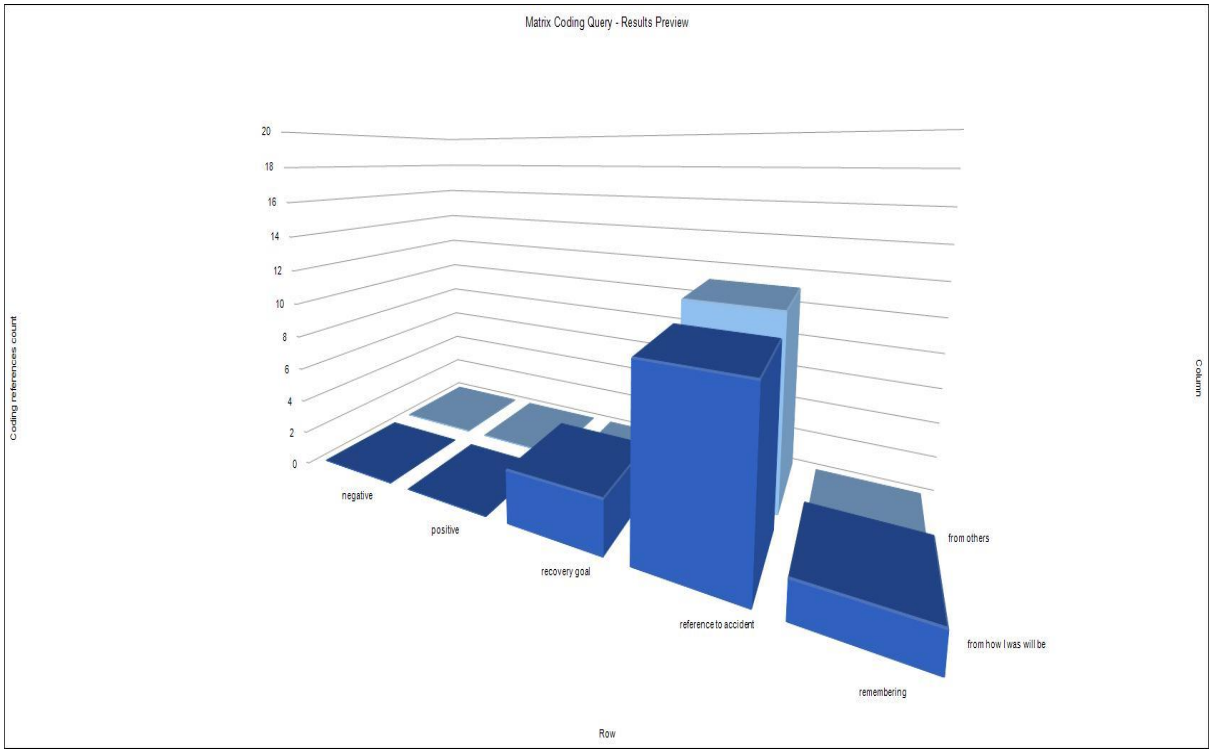

Figure 9-11: Matrix of themes - "being different" and "brain injury"

There was also a link between the references to “psychosocial qualities” in relation to “brain injury” (see Figure 9-12). The children and young people could see the impact that their brain injury had had on their previous qualities and how things had changed for them as a result of their brain injury:

> *Like before, I could handle things but now I can’t handle things and it just stresses me out (Debbie)*

> *Some traits of my personality have stayed the same even through brain injury (Tracey)*

> *Just after my incident like I say I was quite fatalist, I didn’t think I’d amount to anything. Just before it I’d …I didn’t have a care in the world to be honest. I was l only in year 8/9. I just took each day as it comes, I was a happy go lucky kind of person (Stuart)*

I've had like a rocky teenage life basically, so I don't know, I think it's made me see from other people's perspective differently …Yeah I've been there and I've experienced what it's been like to not feel so good (Amelia)

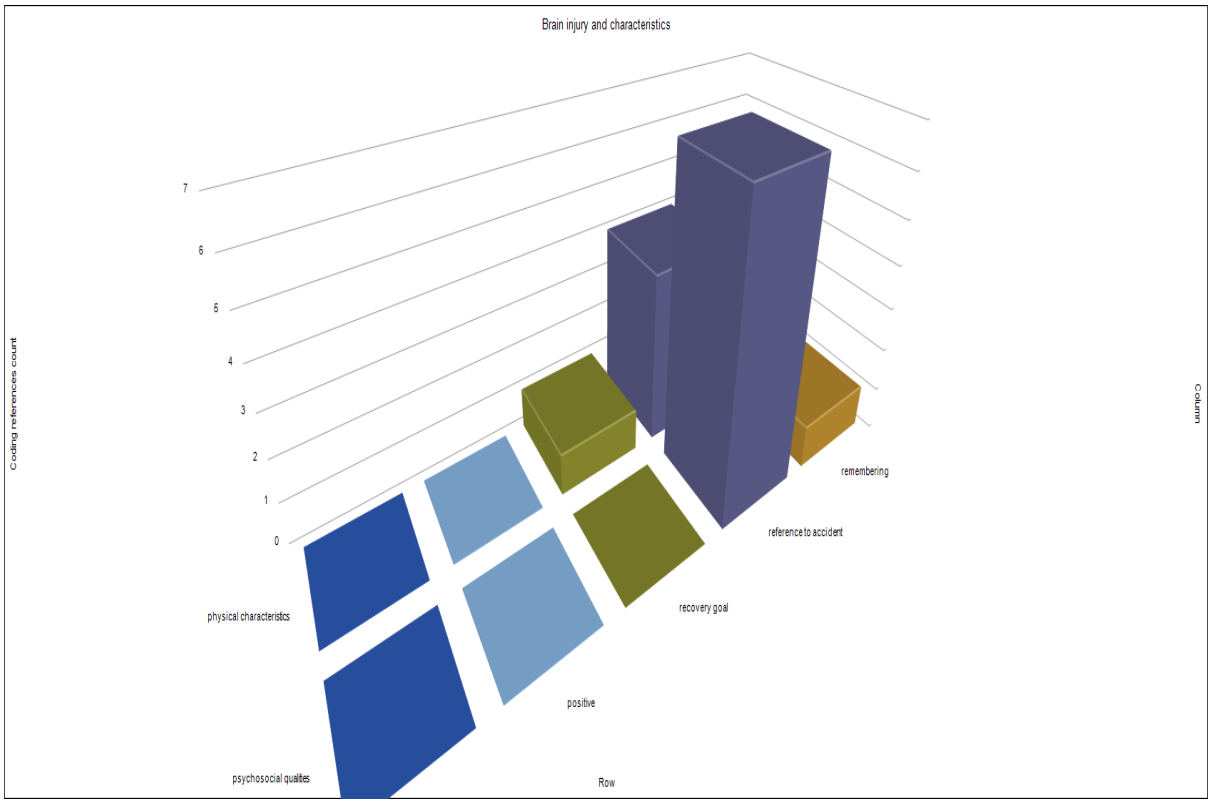

Figure 9-12: Matrix of themes- "brain injury" and "characteristics"

Some of the children and young people made particular reference to how they had adjusted to their brain injury. In three interviews (two cases) there was a negative adjustment. One case wondered if she would ever "get over it" (Amelia) and the other chose not to talk about it because it was sad (William). On the other hand there were five interviews (four cases) who described positive adjustment (Debbie, Tracey, Stuart and Kevin).

So I think that me having my head kicked in did sort of help me stay on the right path and taught me who my real friends are and so I stopped socialising with the wrong crowd and sort of got on with it (Stuart)

I think my accident's had a huge effect on me … It sort of gave me the chance to look back at what's going on do you know what I mean instead of taking every day as it comes like I do now (Kevin)

I would never regret getting run over right cos I've met some great people (Debbie)

It's sad that it took such a big thing for it to change me but I think it was for the best like, not like that cos I think it was, bringing me down to reality and into the real world. I think that was the bit (Tracey)

These four cases were 17-19 years at testing and three of the cases were in their 4th year post injury. All four of these young people had narrative in their SUI interview data that was typical of their age.

The theme of brain injury was understandably also evident in the interview data from the KIC. The structured questions directly probed the child/young person's knowledge of their own brain injury and provided an intersting insight into how able they were to describe the events of their accident. In most of the cases the children/young people did not have a full narrative of their own and were reliant on what others had told them.

People have told me cos I remember nothing (Amelia)

I don't remember none of it (Debbie)

They just told me I was riding my bike and I got hit by a car (Peter)

In some cases they had a vivid recall of the events leading up to accident and then nothing afterwards.

I remember like the accident was on a Sunday I remember the entire Saturday I remember, I wasn't , I wasn't actually, the week building up to the weekend I hadn't, I hadn't handed in my history coursework, my GCSE coursework and Mum got a phone call from the school saying "xxxx's not done her coursework, handed it in on time, bla, bla, bla" Mum said to me "if you don't do the piece of work and hand it in this week you're not allowed out at the weekend" so I rushed it got a crappy, crap grade for it, handed it in went out that weekend. Saturday I was dancing from 9 til 5 as normal, come home, got changed…….and then I looked at her…..was up in the air that's the last thing I can remember (Tracey)

In other cases the first thing they were able to recall was being in hospital

I can't remember anything about it. I remember like being in hospital and like after like I woke up and stuff but I didn't have a clue what was going on. Family have told me stuff (Rosie)

I don't remember being hit by a bus. I only remember getting to the crossing and crossing the .. then that was it and then I had dreams and then I woke up in hospital panicking wanting to get home (Dale)

Another section of the KIC contained some questions that directly probed the child/young person's knowledge of brain injury in general and knowledge of the general consequences. Some had a very detailed knowledge of how the brain works including neuroanatomical and neruophysiological information that they had

learned and remembered either from science at school or from brain injury education sessions from specialists

> *It controls everything. I know what most lobes control. I know which lobes of mine are damaged. Synapses and neurones and all that stuff (Tracey)*

> *They tried to teach me about it in rehab but I didn't really want to know (Debbie)*

> *I did this for psychology actually Any time that your brain detects stress hypothalamus picks it up, that sort of sends signals to your adrenal glands…… (Stuart)*

There were many descriptions of what the brain was like including blamange, mashed potato, spaghetti, size of your fist, pink and sqidgy, gooey, pink, 1¾kilos. The children/young people were also asked if they knew what happened to the brain in an accident. Four of the children/young people answered with a direct "no". Of those who offered an answer their answers were often factually correct:

> *Yeah it shakes about I don't know it just becomes damaged and sometimes it can't be repaired (Dale)*

> *Damages it and damages the cells and stuff (Lee)*

> *Moving brain back and forward and side to side (Robert demonstrated)*

> *Umm it can die, it can be stunned, permanent damage (Tracey)*

> *It can swell up (Rosie)*

The children/young people were asked questions relating to coma. They were asked if they had heard the word, if they knew what it meant and if they had been in one. Many responses related to sleep e.g. asleep, deep sleep, sleep for a long

time, very deep sleep, go to sleep for months, a permanent sleep. Other responses related to the machinery and the concept of life support:

> *It's like well you're on a life support machine and the machine's breathing for you (Peter)*
>
> *I think is it just the life support machine. It just keeps your heart pumping and breathing right. Erm, I'm not sure what it does to the brain (Kevin)*

These interview results demonstrated that the children and young people in the study commonly express themselves in the psychosocial domain. In addition, they have a common theme regarding their brain injury and how they have changed as a result, again relating that to the psychosocial domain. When directly questioned about their brain injury or brain injury in general, they have a broad range of memories and knowledge.

9.5 Cross-case analysis by age at injury

The cross-case analysis of profiles in the first section of this chapter presents the cases in the order of amount of discrepancy from others and from the norm. With the exception of Rachel, it is noted from these profiles that the younger (at injury) children are clustered together and present with the most self-others and self-norm discrepancy. This pattern was not replicated for the children and young people who were older at injury (see Figures 9-1 and 9-2).

The children and young people's data were ordered by "age at injury" and explored across the measures at T1. There was no correlation between the age of the child at injury and the mean scores of the Harter scales, the total scores of the SDQ or the Cooking Task (see Tables 9-5 and 9-6).

There was a correlation in the data of the SUI at T1. There was a significant reduction (p<0.05) in the scoreable chunks assigned to the physical and active domains with age at injury across the fifteen cases (see Table 9-6).

Table 9-5 Correlations between 'age at injury' and 'time since injury' for the Harter Scales at T1

	Harter Scales							
	Scholastic competence (n=15)	Social acceptance (n=15)	Athletic competence (n=15)	Physical appearance (n=15)	Job competence (n=13)	Romantic appeal (n=13)	Behavioural conduct (n=15)	Close friendship (n=13)
Age at injury	.01	.26	-.30	.05	.05	.28	-.33	-.15
Time since injury	.32	.21	.24	.18	.16	.13	.19	-.13

Note *correlation significant at the p<0.05 level

Table 9-6 Correlations between 'age at injury' and 'time since injury' for the SDQ, Cooking Task and SUI at T1

	SDQ	Cooking Task	SUI – percentage chunks allocated			
	Overall Stress (n=13)	Number of errors (n=9)	Physical (n=15)	Active (n=15)	Social (n=15)	Psychological (n=15)
Age at injury	-.37	.22	-.55*	-.48*	.15	.00
Time since injury	.20	-.57	-.25	.28	-.02	.46*

Note *correlation significant at the p<0.05 level

There was a common theme of “brain injury” in the thematic data from SUI. Further investigation demonstrated an age at injury relationship in this theme. Children and young people over the age of 12 years at injury, and more so for the group over 16 years at injury, were more likely to make reference to their accident (see Figure 9-17).

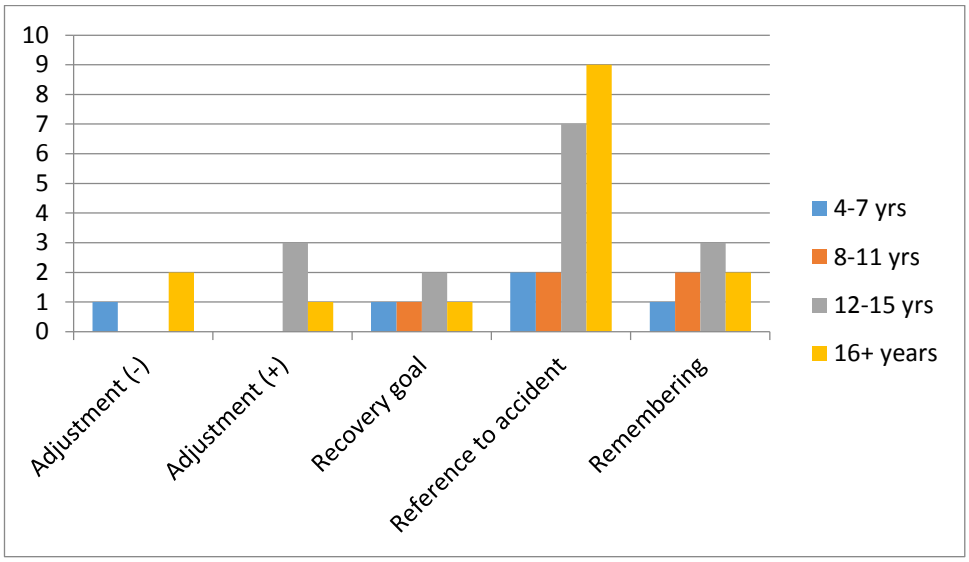

Figure 9-13: Relationship between "brain injury" theme and age at injury

These data show an age at injury trend with the younger (at injury) children demonstrating a greater self-other and self-norm discrepancy. Furthermore there was some age at injury pattern in the detailed data.

9.6 Cross case analysis by time post injury

The cross-case analysis of profiles was reviewed again, this time with regard to time since injury. Time since injury did not seem to have an effect on the order of these profiles (see Figures 9-1 and 9-2).

There was one significant correlation between test scores and ‘time since injury’ (see Tables 9-5 and 9-6). There was a significant (p<0.05) increase in the

percentage of chunks allocated to the psychological domain with the passage of time post injury.

In the interview data (SUI) there was a relationship between time since injury and the theme “brain injury”. The children and young people in the first 2 years post-injury were more likely to make reference to their accident (see Figure 9-18).

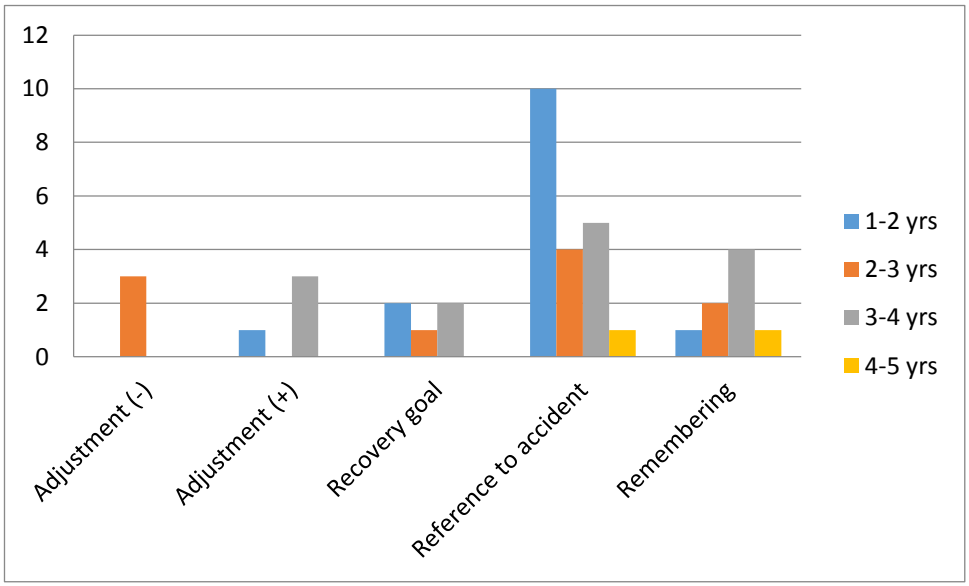

Figure 9-14: relationship between "brain injury" theme and time since injury

9.7 Change over time

Ten cases had change over time data. The details of their individual changes are reported in the previous chapter. They all had changed circumstances over the time being measured. The biggest changes were that they returned home from rehabilitation settings, left school, started work or college. But even those who remained at home and at the school changed teachers and went up at least one school year.

A summary of change across time was generated by reviewing whether the scores on the different measures went up, down or stayed the same (see Table 9-4).

Vertical arrows indicate the direction of change over time and a horizontal arrow indicates no change.

Table 9-7: Cross-case analysis of change over time

	KIC Knowledge	KIC No. difficulties identified	SDQ Overall stress	SUI Mean	Harter No. items below norm
Henry	↑	→	→	↑	→
Rupert	↓	↑	→	↓	→
Amelia	↑	↓	→	↑	↓
Lee	→	↑	→	↑	↓
Robert	↑	↑	↑	→	→
Tracey	↑	↑	→	↑	↓
Debbie	↑	↑	→	↑	↑
Stuart	↑	↓	→	↑	↓
Rachel	↓	↓	→	↑	↓
Dan	↑	↓	n/a	→	↑
	7↑	5↑	8→	7↑	5↓

KIC – Seven of the ten cases demonstrated a greater knowledge of their accident and greater knowledge of the brain and how it can be injured in an accident. In five cases they identified more areas of difficulty than they had on the initial visit. However, there is no comparison data from the parents at T4.

SUI – Nine of the twelve cases demonstrated an increased mean value in the scoreable chunks of interview data across time.

SDQ – Nine cases completed SDQ for three or four research visits. They all scored within the average range for "Overall stress" at T1 and eight of the nine remained at that level. One case (Robert) had a **slightly raised** self-rating score at T4.

Harter – The number of items below the norm level was calculated for those who remained in the study until T3 or T4 ie at least 1 year. In three cases the number increased and in seven cases the number stayed the same or decreased. Rachel's

T3 score was used as she stopped the data collection at T4. Athletic competence was the item that remained below the norm for the greatest number of cases (8).

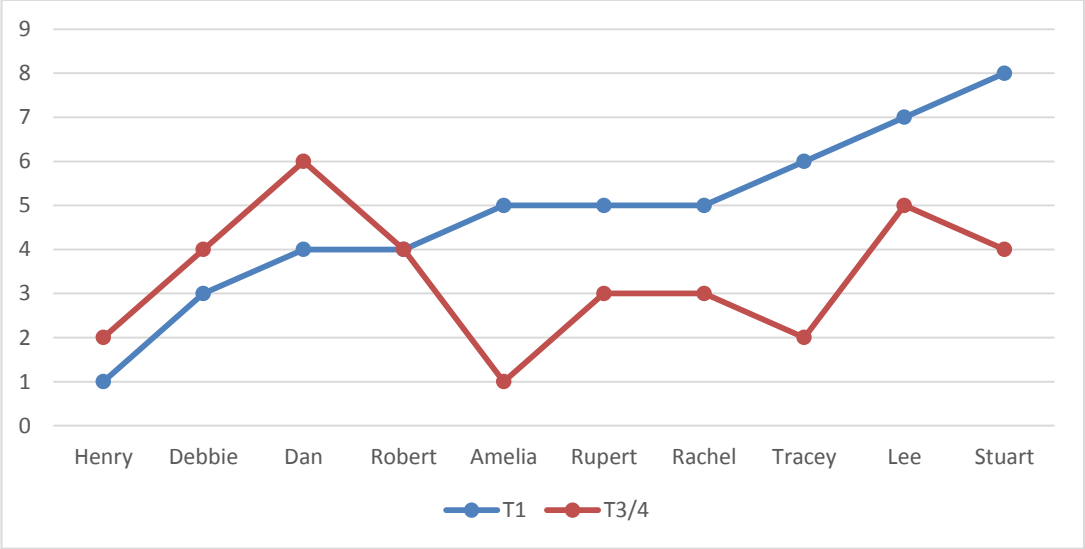

Figure 9-15: Change in the number of items below norm in Harter Scales

These data demonstrate that the children and young people made changes over time. The trend across the cases was to become more closely aligned to the norm values in the Harter Scales (see Figure 19-9).

9.8 Summary

This chapter has attempted to provide a far reaching cross-case analysis by reviewing both the general and specific trends in the data that was gathered from a range of sources and at multiple time points.

1. *Explore the profile of self-awareness following moderate to severe TBI in childhood*
2. *Compare the profile to typically developing children as reported in the literature*
3. *Explore the profile of the ongoing development of self-awareness following TBI in childhood*

4. *Compare the ongoing profile to typically developing children as reported in the literature*

All of the above research questions were addressed in this chapter, although more emphasis was on the profile of the participants (covered in questions 1 and 3) and investigating if there were injury-related or age-related factors that accounted for the patterns that emerged in the data. There were no clear common characteristics in the participants who had similar scores on the different measures. There were general trends in the discrepancy data across cases and across domains. The greatest self-others discrepancy was in the social and behavioural domains, and the greatest self-others discrepancy was in the school/learning and physical domains.

These trends were compared to typically developing children in order to further address research questions 2 and 4. There were age-related trends in the data ie greater reference to the physical domain in participants who had their brain injury at a younger age.

The patterns in the data across time have also been reported. These cross-case patterns, how they relate to theory, and how they are of interest to the clinical team will be discussed fully in the next chapter.

10 Chapter 10: Discussion of findings

10.1 "Extremely complex melting pot"

At a recent conference Professor Jennie Ponsford spoke of the complexity of brain injury[15]. In her keynote address she described three cases with the same neuropsychological profiles that had very different outcomes following their injuries noting that only 20% of the variance in brain injury outcome is related to the injury itself. She continued by exploring some of the personal and environmental factors that influence the outcome of our clients.

Having completed this research study I can not only concur with the sentiments of Professor Ponsford but add further to the melting pot. When it comes to traumatic brain injury in childhood, a further ingredient is added. Child development is a crucial factor to consider when carrying out research with this younger client group.

Not only is brain injury recovery complex but self-awareness is also a complex phenomenon that has a prolonged developmental trajectory. This research study has attempted to capture some of the complexity of the phenomena of impaired self-awareness with this particular client group. The researcher utilised mixed methods and a range of measurement instruments from both typical development and clinical research with a data collection schedule that yielded a large amount of data across time.

Despite the difficulties of managing extensive data, some patterns and profiles started to emerge across the cases in this research. As reported earlier, the mixed

[15] 10th World Congress on Brain Injury, San Fransisco March 2014

methodology writers suggest that complex phenomena are beyond the scope of single methods (Morse and Niehaus, 2009). But the complexity of brain injury in childhood is also challenging to the single researcher. Self-awareness as a specific mental function of ICF-CY has the recommendation that it is assessed by multiple measurements or modes of assessments, multiple informants and multiple settings (Lee, 2012).

The overall aim of this research is to gather quantitative and qualitative longitudinal data from children and young people who have experienced a moderate to severe traumatic brain injury in order to understand their level of self-awareness.

Based on the results of this study, this chapter will provide new insights into self-awareness following a brain injury in childhood and revisit the theoretical models from the adult literature. With fresh insights, the elements that may be relevant to include in future theory development of self-awareness after a brain injury in childhood will be suggested. A new definition of self-awareness in children and young people with a TBI will be proposed.

Thereafter, the chapter will present the broad findings of the research in relation to the wider clinical team. Furthermore, there will be a discussion of the findings that particularly relate to occupational therapists. Finally, the chapter will close with a reflection on the ethical issues, limitations, and recommendations for clinical practice and future research.

10.2 Theoretical considerations

10.2.1 Development of theory

In line with the findings of a recent study published since the completion of this study, the results from this research indicate the need to re-evaluate the models of self-awareness that have been commonly adopted in the adult literature [Toglia & Kirk (2000) and Crosson et al (1989)] within the context of child development. Crosson and colleagues (1989) proposed a hierarchical model including intellectual awareness, emergent awareness and anticipatory awareness. Alternatively, Toglia presented a more dynamic interaction of the elements of concern including domains of concern, on-line awareness, metacognitive knowledge and beliefs. These models are reproduced below for reference (see Figures 10.1 and 10.2).

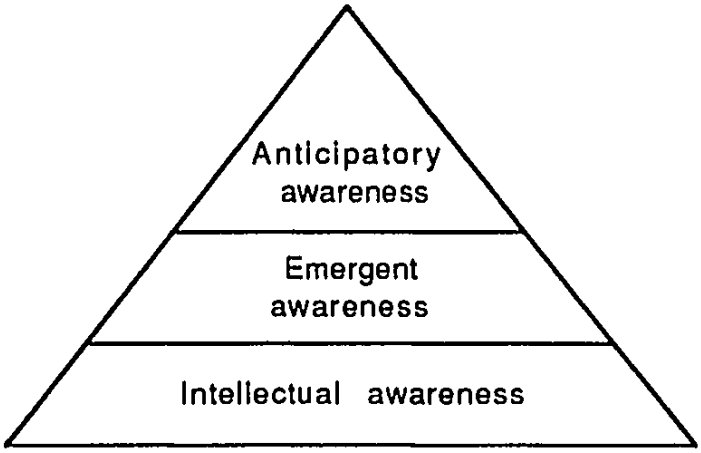

Figure 10-1 Awareness represented as a pyramid (Crosson et al, 1989)

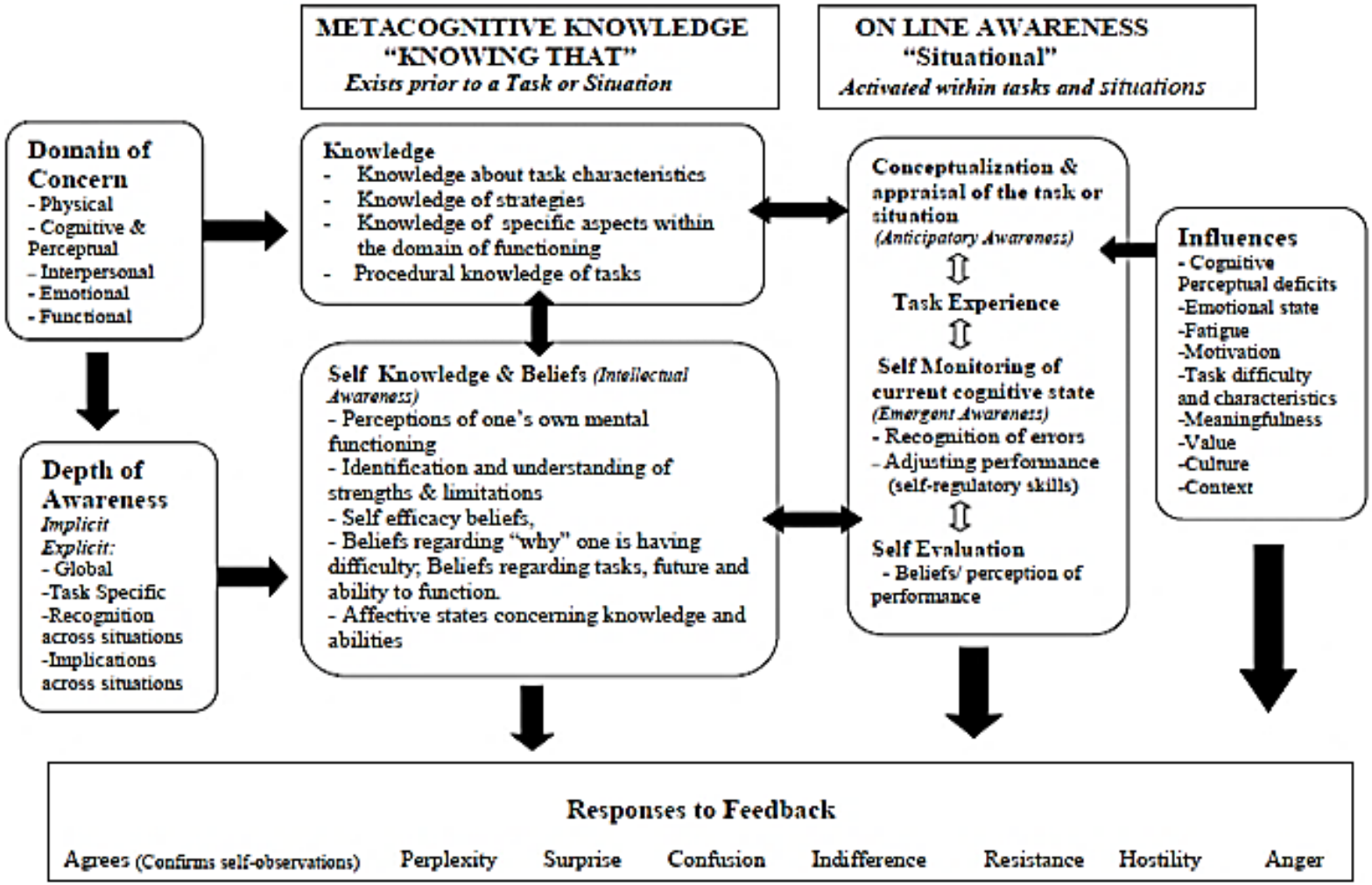

Figure 10-2 Comprehensive model of awareness (Toglia and Kirk, 2000) Reprinted from Publication title, Vol number, Author(s), Title of article, Pages No., Copyright (Year), with permission from IOS Press

Neither of these models considers the child's age and developmental level. They do not consider that knowledge, experience, and the multidimensional nature of self-awareness may all have different trajectories. Each of the elements of these models requires adaptation and explanation to accommodate a developmental focus. For example, the 'Domains of concern' in the Toglia & Kirk model are subject to developmental maturation. Adults have an integrated sense of self that is active in all functional domains. However, we have learned from developmental psychology models that the young child is concerned with the physical domain and develops a growing awareness of the social and psychological domains with increasing age. Furthermore, at an even more fundamental level of knowledge, a young child does not have knowledge of how the body works, and has little knowledge and experience of how tasks are meant to be completed. This developmental lack of knowledge and experience is not accommodated in the adult models.

Recently, other researchers have also considered how to accommodate new theoretical ideas about self-awareness in childhood into the adult models (Krasny-Pacini et al., 2015). These authors focus on the assessment of the cognitive/metacognitive domain of function following traumatic brain injury. They also reflect on the adult models and find them lacking some essential elements of developmental psychology. They propose a framework for assessing awareness in children and suggest methods for assessing different components of awareness (on-line awareness, intellectual awareness) while acknowledging the difficulty

assessing anticipatory awareness. The client group that was used to formulate the framework were involved in a metacognitive training programme. While the framework is an encouraging contribution to the development in theory in brain injured children, all functional domains including motor, social and communication etc., should be explored for a framework to have greatest utility in the rehabilitation setting.

The data in this study suggests that there are some important elements that should be considered as new ideas are formulated for children/youth following a brain injury. New frameworks of self-awareness may want to consider the importance of cognitive development, children's experiences, and ability to reflect and make future evaluations in relation to their newly acquired deficits following a brain injury.

There are illustrations within these data that give tentative direction to the ideas that may require further exploration. Firstly, many of the children did not have a clear narrative relating to their accident (Knowledge Interview for Children; see section 9.3.2). In some cases the child may have been protected from the trauma of discussing these events. However, there is also a developmental issue relating to the maturation of autobiographical memory in young children. Children and young people who have cognitive deficits following their injury would require more repetition or support with new information, particularly if they have difficulty with

abstract thinking at an age appropriate level (see section 9.3.4 and individual cases in chapter 6). Knowledge seems to be an important factor to consider.

A child's reflective ability is a second factor that should be considered in future theoretical development of self-awareness following a brain injury. Younger children lack the experience and knowledge of how tasks should be performed and are still reliant on feedback from the adults around them. Children/young people may be carrying out new tasks, with new strategies, in the rehabilitation setting. They may need additional adult support initially to recognise the need for supports in this new environment. Some children/young people in this study benefitted from doing tasks in context (The Cooking Task) or talking about familiar contexts (school) to give more accurate reflections. Context may be another important element for theoretical consideration of self-awareness, which is particularly pertinent to brain injury rehabilitation.

A third factor that seems relevant to future theoretical considerations of self-awareness after a brain injury in childhood is the child/young person's ability to make future plans related to their newly acquired deficits. Future and abstract thinking is particularly challenging for children as they mature, and is a factor that should be given careful consideration when developing theories that are unique to children's self-awareness. This study illustrated children/young people who had difficulty thinking of themselves in the future, scoring below age expectations on

the Self-Understanding Interview (see section 9.3.4 and individual scores in chapter 6).

Future research should consider the factors outlined here to construct new developmental frameworks of self-awareness following a brain injury in childhood for proposal and testing.

10.2.2 Towards a new definition of self-awareness after a TBI in childhood

The initial sections of this chapter have considered the development of theory of self-awareness following a childhood TBI. Following on from this, further consideration is now given to the existing definitions of self-awareness from adult brain injury and child development literature. The definitions in the adult literature make no mention of self-awareness being an evolving construct (Dirette et al., 2008a, p44). It is therefore appropriate to present a new definition as follows:

> ***Self-awareness of deficits following a brain injury in childhood is a dynamic and complex construct. At its earliest level it is an adult-supported reflection of ability in the physical domain. Through maturity and recovery there is an ability to appreciate a range of deficits across domains, and anticipate their effect on functional performance.***

This definition incorporates the notion that there are many aspects to the development of and recovery of self-awareness in childhood. The definition acknowledges both the maturational and recovery perspectives.

10.3 Measuring self-awareness in children and young people with TBI

As mentioned above, it is recommended that complex constructs are measured with a range of measures. A far reaching assessment was achieved in this study by using five measures, including one from clinical practice (SDQ), two from child development (Harter Scales and SUI) and two from brain injury (KIC and Cooking Task/Executive Function Map). While it is acceptable to have this broad range of measures within research protocols, it is likely to be overly burdensome for busy clinicians. A reflection of the measures in this study will follow, to help inform clinicians and researchers of a suitable assessment protocol. This section will contain recommendations for further development of tools to measure self-awareness following brain injury in childhood. In adult studies, it is common to measure a discrepancy between self-report and the report of others (Hart et al., 2009). There were parallel versions of the Harter Scales, SDQ, KIC and Executive Function map. With scores from teachers, parents and the researcher, it was possible to replicate this method of scoring a discrepancy. All the measures were accessible, but there were a few issues to consider from all informants. The children and young people found the Harter Scales rather lengthy, and some participants commented on the large number of items. Despite this, they all completed all of the items for the sake of the study. They may be less inclined to complete it in clinical practice, when they are being asked to complete assessments in many of their therapy sessions. There were also a few teachers who failed to

complete items related to the physical appearance of a child. They reported that it was inappropriate to comment on whether the child was attractive etc.

In addition to the research and clinical utility of these measures, there are also some more philosophical issues related to the efficacy of informants report. Who has the ultimate "truthful" score against which to measure the discrepancy? All informants could provide potentially flawed data. Some teachers had known the child before the accident. If the child was achieving well before the accident, the teacher may feel awkward about scoring the child at a reduced level now. This is particularly an issue if the teacher knew others involved in the accident etc. The parent may still be coming to terms with the newly acquired difficulties that their child is experiencing. There may be associated feelings of grief and guilt, and the parent may not be an accurate responder. The child may have been much protected since the accident, and may have had reduced opportunities to experience failure. They may genuinely not know about their newly acquired difficulties.

Measuring against the norm may be the more accurate measure. Developmental measures were chosen for this study with the intention of providing a robust benchmark against typical development. Unfortunately, there is a wide variability of self-reporting in the typically developing population. While there is a developmental trajectory, there is a great deal of variance within the dynamic construct of self-awareness. The mean scores can decrease, as well as increase, at

particular ages. This being the case, it may look like a child is discrepant from the norm but we may just be seeing normal variation in scores. As a result, the developmental trends were found to be more useful than the mean scores in this study. The cases were summarised with reference to the Harter pen portraits and the expected trends in the SUI, giving a comparison against the general expectation of their age-matched peers. Further research is necessary to establish if a more robust comparison of such a dynamic construct is achievable.

Neither the adult method of measuring self-awareness, nor the method of measuring against the norm has in fact been totally adequate. The measurement issues are closely related to the theoretical issues. In order to measure the construct of self-awareness following brain injury in childhood, we have to fully understand what it is. However, it is likely that more than one measure will be necessary in order to assess a child/young person's level of self-awareness.

As suggested above, it may be important to know the child/young person's level of knowledge of brain injury in general and details of their own narrative. Also, we want to know whether the child/young person has knowledge of their newly acquired difficulties since their brain injury. The KIC has only been used in one other published study (Beardmore et al., 1999). It was easy to administer and the children and young people were able to engage with it. However, the tool warrants further development as there were difficulties with the scoring guidelines and there may be benefit in adding some more questions. The question regarding feelings

and behaviour would benefit from dividing into two separate questions and the measure lacks questions regarding the social domain. Questions regarding getting along with friends, starting and maintaining new friendships would be indicated as psychosocial issues are highlighted in recent literature as a significant factor in brain injury recovery (Anderson et al., 2006, McKinlay et al., 2009). It is possible that the psychosocial aspect of this measure could be developed. Development of the psychometric properties of the KIC may provide a tool that can inform us self-awareness knowledge in childhood. Additionally, it is important to understand whether the child/young person is orientated to the physical domain or has made some developmental gains towards the social and psychological domain. The SUI and the Harter Scales provided important data in this study, and informed the developmental level of the children and young people. However, the measures were not developed specifically for this purpose despite the constructs of self-understanding; self-perception and self-awareness having an overlap in their concepts. Development of a new measure with norm data would be required. In particular, ranges of normative data should be collected, in addition to mean scores, to reflect some of the dynamic and wide ranging levels of self-awareness that exist among typically developing children.

Measures to assess elements of self-awareness that include reflection and future planning have been introduced in a recent publication (Krasny-Pacini et al 2015). The authors consider The Cooking Task as a contextual measure of awareness and this is discussed further in section 10.5.1 below.

10.4 Clinical team messages

The findings that will provide the broader clinical team with greater understanding of addressing self-awareness following a brain injury in childhood are first to consider the adult literature. Next, the clinical team should consider how interrupted development has affected self-awareness, and the impact of an altered self-awareness on their therapeutic relationship.

10.4.1 Comparison to adult literature

As in adult research studies there is evidence of the presence of impaired self-awareness in this group of children and young people with TBI. There is a lack of agreement between self-report and that of others (parents, therapists and teachers) which pervades all functional domains. However, in many of the cases, the impaired self-awareness is not complete and there is some, but not a consistent, level of agreement of the difficulty. In these cases the area of difficulty was reported on one measure and not on another. It is not an all-or-nothing presentation.

Having an emerging sense of self-awareness is something that is evident in the hierarchical model of self-awareness presented in the adult literature (Crosson et al., 1989). Despite the apparent applicability of the hierarchical aspect of the model, the remaining aspects of the model are not as easily applied to children and young people. To achieve a higher level of self-awareness, the model states that the patient should be able to recognise and use strategies, a cognitive ability that develops slowly across childhood (Flavell et al., 2002, Small and Kagan, 1990). The

hierarchical construction of this model does not give enough accommodation to all the developmental aspects in self-awareness.

The adult literature also presents evidence that there are particular domains of function that are more easily recognised. In particular, there can be greater awareness of deficits in the physical domain. Authors purport that items that are concrete and observable are more easily recognised (Hart et al., 2004, Toglia and Kirk, 2000). Young children are typically more concerned with the physical and material aspects of self and through development are more able to articulate self-awareness in the social and psychological domains (Harter, 2012a, Damon and Hart, 1988). Therefore if a young child was unaware of his physical deficits it would be less of a concern than an older child.

In a large study of teenagers and young adults with TBI, there was least agreement in the cognitive and behavioural domains (Viguier et al., 2001). The current study does not endorse the findings in either the adult studies who report most discrepancy in the physical domain or the young adult/teenager study. Across the cases in this study, the domain with the greatest degree of self-other discrepancy was social. This study differed in the recruitment of younger children. While the cross-case data from this study suggest that the youngest children have self-other discrepancy in the physical domain, they also have the greatest amount of self-other discrepancy in total.

There was only one case where there was agreement with others in the physical domain. This was the case with the greatest level of self-awareness measured by the overall self-other agreement. Although this is only one of fifteen cases, it is important in case study research to pay particular attention to individual cases that are different (Yin, 2009, Miles and Huberman, 1994). Further scientific investigation may reveal how significant a discrepancy in the physical domain is. It may be that the presence of intact self-awareness in the physical domain is indicative and predictive of self-awareness across other domains. As with the acquisition of self-awareness in typical childhood, perhaps the same process of developing awareness of physical skills has to emerge first in the recovery phase following a TBI in childhood.

The data from the Self-Understanding Interviews were able to capture whether the children and young people demonstrated this age-related trend post injury. When compared to the normative trend, the cross-case analysis matched the age-related trend of less focus on physical domain and more towards the social and psychological domain. Using the measures from typical development in this study, it appears that the awareness of deficits in the physical domain is related to a developmental issue and not related to physical difficulties being more obvious. The Self-Understanding Interview was able to provide important information about the developmental level of the children/young people. However, it also provided data regarding their brain injury and the influence it has had on the children/young people. The Self Understanding Interview is not about brain injury, but the children

and young people mentioned their brain injury 84 times across 23 interviews. Clinicians in the multidisciplinary team may wish to consider the merits of the assessments used in this study. The Self-Understanding Interview may be of particular interest to speech and language therapists and psychologists who may be particularly focussed towards the content and structure of the young people's interviews.

A further topic of discussion in the adult literature is the risk of developing greater self-awareness balanced with the risk of the emergence of emotional distress as a result (Brown et al., 2009, Cooper-Evans et al.). The data in this study indicated that the majority of the cases had a typical level of self-reported stress that remained stable over time, even in the cases where there was evidence of greater self-awareness over time. This is an encouraging and perhaps somewhat unexpected result as the children and young people have endured such a traumatic experience. The SDQ is an instrument that may be valuable for a clinical team to consider for evaluating self-awareness and stress across the cognitive, behavioural and psychosocial domain. The assessment has strong psychometric properties and was accessible to the young people in this study. They were able to relate to the style of the questionnaire and found it easy to rate themselves against the descriptions. The teacher version was not used in this study as preference was given to a more school-orientated measure and unfortunately the self-report version was only available to those over 11 years. Therefore this measure alone

may not be sufficient as a measure of self-awareness across all ages in a clinical setting.

10.4.2 **Interrupted development**

The inclusion/exclusion criteria determined that all the children/young people had typical development up to the point of their brain injury. It can be assumed that their scores on the developmental measures used in this study (Harter Scales and Self-Understanding Interview) would have fallen within norms pre-injury. At testing, all of the children and young people had a score below the norm in at least one area of the Harter Scales and at the upper age range they were not reaching the ceiling across either the Harter Scales or the SUI.

The self-report data profiles of the children and young people in the study indicate that the trajectory of the development of self-awareness has now been interrupted. Although the children who were youngest at injury were the most impaired, age alone did not account for the order of the cases when ranked by the amount of discrepancy across domains. Injury severity and time since injury were also explored but again they did not account for the variability in these cases.

It is important that clinicians understand that children and young people may no longer have self-awareness at an age appropriate level following a brain injury. However, further research is required to explore the reasons why children and young people no longer fall within the typical range for their age across many domains following a brain injury.

It was encouraging to note that the children and young people made developmental gains during the data collection period. Change in this area was an unexpected result. Rehabilitation of high level cognitive skills such as executive function tends to focus on environmental supports and use of strategies (Glang et al., 2008). Remediation has more recently been supported, but only for lower cognitive skills such as working memory (Slomine and Locascio, 2009). Another aspect of change was that the young people tended to answer the interview questions more fully on subsequent visits. Although this could reflect an increasing ability over time, there is also a possibility that some of the change could be accounted for as familiarity. Maybe the children/young people were more at ease as the study progressed, were more comfortable with the interview process and became more familiar with the interview schedule. This degree of familiarity may have facilitated a more dynamic interview.

Maturation in self-awareness would be expected in typically developing children but due to a lack of research evidence regarding children and young people with a brain injury, a similar developmental change may not be anticipated following a brain injury. However, the data in this study supports the idea that as with typical development, self-awareness remains a dynamic construct following a brain injury.

10.4.3 **Therapeutic relationship**

Analyses of the interview narratives provide some very useful insights for working with this client group. These insights are important to review for the purposes of self-awareness intervention. Clinicians who wish to work alongside these children

and young people and improve their self-awareness must realise that it is delicate and sensitive therapeutic work (Marcantuono and Prigatano, 2009). Some important information was gained during the interviews that will help the clinician to understand the child/young person's perspective, for example the priority of relationships over brain injury, particularly as time passed.

The final thematic structure from the semi-structured interview data (Self-Understanding Interview) is in fact more resonant of typical adolescence than may be expected. The typical adolescent is concerned with developing a social life, transforming family relationships, developing values and attitudes (Coleman, 2011, Hendry and Kloep, 2012) and all of these themes were present in the semi-structured interview data. The difference from typically developing young people is the presence of two additional themes, "being different" and "brain injury". The children/ young people are concerned that they are different from how they used to be as a result of their brain injury and they are also aware of being different from others.

In some of the cases, the children/young people presented with a counterintuitive positive reaction to their injury. For example, in one case a young lady stated "I would never regret getting run over". Although this may at first glance seem a surprising result, it is not uncommon to find this theme discussed in the literature. A recent review (Barskova and Oesterreich, 2009) addressed the issue of Post-traumatic growth in a range of serious medical conditions including cancer and

rheumatoid arthritis. The authors found that post-traumatic growth varied across diseases and suggested further investigations within each condition. In the adult brain injury literature there is some evidence relating to post-traumatic growth following a brain injury that is not affected by severity (Hawley and Joseph, 2008). Authors report that it develops over time (McGrath and Linley, 2006, Powell et al., 2007) and once established remains stable in the longer term, up to 11 and 13 years post-injury (Powell et al., 2007, Powell et al., 2012). The current study is the first to report similar findings in a group of young people. Three of the four cases reported who spoke of positive adjustment were in the fourth year post-injury, supporting the gradual emergence of this phenomena. Interestingly the cases who demonstrated Post-traumatic positive growth were between 17 and19 years of age and a similar narrative was not found in the younger children. In fact, the youngest child said that he didn't like to talk about his accident because it made him sad. Again, there may be a developmental issue here that warrants further investigation through clinical research.

Although the children and young people made reference to their brain injury, clinicians should understand that it is not their only concern. They are also very concerned with the everyday issues of childhood including whether they are liked, what they want to be in the future, how important friends and family are. The clinical team are understandably focussed on the child/young person's brain injury, the consequences and recovery. However, these data remind the clinical team to also be knowledgeable about typical development and appreciate the issues that

are important to the children and young people in order to enhance their therapeutic relationship.

The data from the structured interview (Knowledge Interview for Children) also afforded the clinician some important insights. Of primary importance was that most of the cases in this study did not have a narrative regarding the events of their accident. However, there is no indication of whether the child/young person was not given this information or whether they have forgotten. It could be that the parents were reluctant to share traumatic details with their child, that the parents themselves were having difficulty trying to cope; perhaps the moment for sharing the events of the accident passed while the child was very unwell and the family started to "move on" without realising that the child didn't know what had actually happened. As well as being an area for future investigation, there is also a clinical message to the wider rehabilitation team. Children and young people may be confused and anxious and this may have an impact on their motivation to engage in rehabilitation. In addition the therapeutic relationship will be affected if there is an imbalance in the knowledge that the child and the clinician have at their disposal about their personal circumstances.

The children and young people also had a mixed level of knowledge of brain specific information and what can happen to the brain if it is injured. This is similar to the findings of Jacobs (1993) who highlights the additional risk of the child/young person developing some misconceptions. In this study however, the children who

were able to offer some information about the brain were often factually correct. At the later data collection points the children/young people demonstrated a greater knowledge of their accident and greater knowledge of how the brain works. Perhaps the research had prompted them to make enquiries of their family and had gained a greater understanding in subsequent visits. Brain injury education is routinely offered in the centre that the children were recruited from and so they may not be representative of the wider population of children and young people with a brain injury. Regardless, it may be important in the future to consider the need to differentiate this knowledge provision. Currently, there is a "one size fits all" approach and the findings of this study reinforce the importance of taking a developmental approach to all of the clinical interventions offered to this group. The KIC yielded important data that is important to lead rehabilitation intervention and the therapeutic relationship; however, it is still a relatively new measure that has only been used in one other study with children and young people with brain injury. Further development and refinement of the instrument is indicated, in order to improve its psychometric properties.

10.5 Occupational therapy messages

As we have seen, self-awareness following a brain injury in childhood is a concern for the whole clinical team. We have discussed that a child/young person recovering from a brain injury is different from an adult, has an interrupted development and has consequences that will have an impact on therapeutic relationships. But what does the OT particularly have to contribute to the team in

this clinical area? The OT is concerned with the functional performance of the child/young person through the rehabilitation process. The OT supports the child/young person back to school, home and community. The child/young person has a newly acquired set of deficits following their injury and they have to make accommodations in their everyday life. The PEO model that was introduced in Chapter 3 considers the dynamic interaction between the Person, the Environment and the Occupation (see Section 2.8). The interaction of these three elements contributes to the performance of the child/young person in everyday life. Following a brain injury, the OT helps the child/young person achieve optimal performance in their everyday occupations of self-care, productivity and leisure. During these interactions, the occupational therapist supports the child/young persons to accommodate their newly acquired deficits. Interventions may sometimes be directed at rehabilitation of the child/young person's body functions, such as attention, motor control, as classified in the ICF-CY (see section 2. 6). At other times, the assessment and intervention considers adaptation of the activity or the environment. In all of these situations, there is an opportunity to support the child/young person to recognise the impact of their newly acquired deficits for themselves. The following sections will highlight the issues for the occupational therapist, when assessing and supporting self-awareness following TBI.

10.5.1 **Assessment of self-awareness within occupational therapy**

The main areas of concern when assessing self-awareness in occupational therapy are knowledge of development, and appreciation of the importance of context, to support self-awareness within occupational performance.

The data in this study have been collected using a range of measures. Along with the other team members the OT should be aware of the developmental level of the child/young person, and so the measures that have developmental norms will add to the OT's knowledge of the child/young person. The data from the thematic analysis will also remind the OT of the developmental picture of children's occupations. The children and young people referred to how they used to spend their time and how they spend their time now. In one case the young man used to play football. Although he was no longer able to play the game, it remained an important occupation for him and he learned to be a football coach instead. There were interview themes of productivity and leisure/ recreation that were similar to typically developing children. In addition, particular functional information was shared in the second part of the KIC, the Harter scales and the Executive Function Map (used alongside the Cooking Task).

Many OT authors have contributed to the adult brain injury and self-awareness literature. Some authors have highlighted that individuals may have greater understanding of their deficits if they are experienced in context (Dirette et al., 2008a). For example if they do a task that they were able to manage well before their accident, their difficulties may be more easily recognised within the context of

trying the same tasks with support in the therapy setting. The authors describe how “aha” moments may be promoted within the context of everyday occupational performance. The Cooking Task was selected in this study to access tasks that the children/young people may have previous experience of. Cooking is a popular childhood occupation (Wales et al., 2014, Dunford et al., 2005). At an early age children work alongside adults in the kitchen in fun cooking/baking tasks. Over time, children begin to complete more and more of the task themselves (Humphry, 2009). Teenagers begin to engage in cooking as an independence task and make drinks and snacks for themselves and others, as well as continuing to cook and bake for pleasure.

The Cooking Task and the Executive Function Map were easy to administer and the initial scoring of the Cooking Task was easy to carry out. Ongoing development of the Cooking Task is taking place, with translation studies and training programmes currently underway. Further development of the psychometric properties is indicated. Adding normative data to this measure would help occupational therapists to evaluate whether the child/young person’s performance is in line with typically developing children.

In this study, the Executive Function Map was used to facilitate the child/young person’s reflection on their occupational performance. Further study of the usefulness of using the Cooking Task in conjunction with an evaluation tool such as the Executive Function Map would enable the occupational therapist to measure

the more challenging aspects of child/young person's level of self-awareness including future consideration of newly acquired deficits in physical and cognitive domains.

The cross-case analysis indicated that all of the children and young people adjusted their self-rating after the task, as with a previous study of children rating their memory performance(Josman et al., 2000b). In the majority of the cases they lowered their scores but still rated their performance higher than the researcher. As with the adult literature, although the children and young people still overestimate their performance, they benefit from completing a "real life" functional task.

The children and young people's individual result profiles are an important part of the evaluation in addition to the cross-case results. In the individual cases, the results from the assessments will inform the OT whether there are particular discrepancies at school for example. Change over time is also relevant at an individual level. In William's case, his scholastic competence score went down on subsequent visits. He had gone up a school year in the intervening period and with time he had perhaps grown more aware of his difficulties in relation to his peers. Environmental factors such as context play an important part in developing self-awareness.

School is another important childhood occupation (Rodger, 2010a). The results from the cross-case analysis of this study indicated that the children and young

people's self-report of scholastic competence were typically below the norm in this client group. They recognised that they were having difficulty when they returned to school but this was an area where they did not over estimate their performance compared to the teacher report. Interestingly, there was agreement between the self and parent report of "keeping up with the rest of the class" for the majority of the cases, as well as some cases where the child/young person identified the difficulty even when the parent did not. Like with the Cooking Task, it may be that observing their functional ability in the context of the classroom helped both the children/young person and the parents to evaluate their performance. They may be evaluating their ability compared to their pre-injury level in addition to the performance of their peers. This dual aspect of evaluating performance emerges in middle childhood and is part of child development (Eccles, 1999, Harter, 2012a). Class-based observations are often utilised by children's OTs and they should be encouraged to make use of these opportunities to carry out reflections with children following a brain injury.

In addition to the areas of functional performance that have been mentioned previously, the data in this study highlighted that it is also beneficial in brain injury recovery and rehabilitation to consider some of the body functions that may have been affected as a result of the child/young person's brain injury impairment. Self-awareness is itself classified in the ICF as a specific mental function[16]. Occupational

[16] ICF-CY classification codes relevant to self-awareness in the body functions/structures category

therapists while focussing on function, take into account the difficulties in body functions and structures that impact on the child/young person's functional ability.

The occupation-focussed occupational therapist must not overlook two important areas of body functions because of the impact that they have on activity and participation. Fatigue and executive difficulties raise particular concerns in these data. Fatigue is reported by all of the children and young people in this study as an ongoing concern. The children/young people recruited were not in the acute stage post-injury and so fatigue seems to be reinforced as an ongoing issue in the longer term. Similar findings are reported in the literature. A group of Swedish young people with TBI reported ongoing issues with fatigue 5-8 years post-injury (Renstrom et al., 2012). A further Swedish study (Falk, 2013) highlighted early reporting of fatigue and investigated the role of the nurse to support young people with a head injury and their families with a follow-up service. The ICF defines fatigue predominantly as a physical function[17] but some of the reports in these data reinforce that fatigue can be both physical and cognitive. A few of the cases in this study report cognitive and physical fatigue and seem to be aware of the difference. One young lady reported how tired she gets when attending lectures as she has to concentrate so much. There is little research and no specific guidance relating to interventions for fatigue in children and young people following a brain injury and

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B11420 Orientation to self
B1644 Insight
B1800 Experience of self

[17] B4552 Fatiguability – functions related to susceptibility to fatigue at any level of exertion

this is an area for further research. In the meantime, OTs should not overlook this area of concern for young people and may be directed to guidance in other conditions in childhood with fatigue as a main feature (Smith and Crawley, 2013)

Planning/organising was the other area in the body functions component of the ICF-CY that the children and young people had difficulty recognising. Such executive functions mature in adolescence and are less likely to be understood by a younger child. However, they are commonly affected following a brain injury and continue to have an impact on functional recovery in the long term (Beauchamp et al., 2011). OTs are well positioned to work alongside this group of children in everyday tasks and educate the children/young people regarding executive functions within this supportive context. The children will be better placed to respond to strategies if they have some understanding of the impact of their cognitive difficulties in everyday life (Levin and Hanten, 2005, Ylvisaker, 1998a).

10.5.2 **Intervention**

Two key components of brain injury rehabilitation are goal- orientated and child and family centred. The aim of this study was

> To gather quantitative and qualitative longitudinal data from children and young people who have experienced a moderate to severe traumatic brain injury in order to understand their level of self-awareness.

The discussion so far has attempted to outline the impact of a brain injury on the development of self-awareness, both to the wider clinical team and more

specifically to the OT. The next section will address the particular relevance of these data to the rehabilitation process and goal setting in particular. As mentioned earlier in this thesis (see Chapter 3), the definitions of rehabilitation (Royal College of Physicians and The Children's Trust) highlight that rehabilitation for children and young people following a brain injury should be child and family-centred and be goal directed.

An interesting observation was made in the field notes of this research study. A number of the children/young people were happy to have their family members present during the interview. Guidance for conducting research with children and young people advocates that the young person should choose if they want an adult present but the adult should be informed of their neutrality (Shaw et al., 2011). Despite the presence of a parent, the children/young people remained focussed on me throughout the interviews and did not include their parent in the conversations. They did not look towards them and only one parent interjected in the conversations. She then left the room while the interview continued. Perhaps the parent child-parent relationship changes following the traumatic experience of the brain injury and the subsequent rehabilitation and recovery process. The parent is much more present in the young person's life and they become used to being around the interactions with professionals without being actively involved. However, families may have logistical and emotional reasons why this may be challenging and a flexible approach may be required (Foster et al., 2012). Clinicians

should expect that children and young people on their caseloads may wish to have parent involvement more than typically expected with young people.

Goal setting is another area where child and family should work together with the clinicians (Ylvisaker, 1998b, Pollock et al., 2010). Goal setting is a collaborative process that involves discussions between clinicians, children/young people and families. The data in this study indicated that children and young people had some awareness of their deficits and were able to discuss their challenges. However, when interviewing children and young people following a brain injury it may be necessary to break down the questions in to smaller chunks. For example, the structure of the KIC included broad and closed questions. While many of the children had little response to the question "have you had difficulties since your brain injury?" they were able to go on and list their difficulties in response to a structured list. This finding is similar to other authors who report that children as young as six years can be engaged in goal setting if they have resources that are supportive (Missiuna and Pollock, 2000). There are existing tools for goal setting in occupational therapy. Goal Attainment Scaling - GAS (Kiresuk T et al., 1994) and Canadian Occupational Performance Measure - COPM (Law et al., 2005a) are psychometrically sound, widely used tools to facilitate client centred goal setting but additional support from therapist may be required to make the interview more structured. Additional visual resources and additional prompts may be required. Although resources for younger children exist, such as the Perceived Efficacy and Goal Setting tool (Missiuna and Pollock, 2000), they would be too "childish" for

older children and youth. Talking Mats[18] is a commercially available set of picture communication symbols (Murphy and Boa, 2012) or less formally some pictures from Clipart on Word could be used to make COPM and GAS more accessible for older children and young people who require additional structure following a TBI.

The data in this study suggest that individual goal setting in the rehabilitation setting following a brain injury may be challenging to children and young people with impaired self-awareness. Perhaps clinicians should support children and young people to set goals in the physical and functional domains initially. The children and young people in this study made positive changes over time and became more closely aligned to the self-report expected in typical development. It may be that longer term goals can be reviewed and the child/young person may be able to collaborate in goal setting across domains at a more age-appropriate level at a later stage of recovery. It may be that children and young people need family and clinician support initially to set goals in other domains.

10.6 Ethical issues

Ethical issues did not present a difficulty during this study. The extensive ethical procedure and cautious examination of the protocol, research design and methods ensured that the research study ran smoothly.

I was careful not to be coercive at any time and I became aware that individuals had preferred styles and methods of communication such as email, text etc. Repeated

[18] Talking Mats is a social enterprise who support people with communication difficulties – www.talkingmats.com

failures to reach a parent may have been because I was using a method that they were not so comfortable with. It didn't reflect how they felt about participating in the research. Styles and favoured communications should be acknowledged in future research projects whilst being aware of possible issues of privacy when using own mobile telephone. Research teams may wish to purchase a SIM card for team to use in the recruitment stage of the study.

An unexpected circumstance towards the end of the study was the personal feelings of being in a long term follow up study. Dealing with the ending of the researcher/participant relationship was more of an issue in some of the cases. I had known some of the cases in the clinical setting and so the contact both clinical and research had lasted over a number of years. Managing endings may be more of an issue in clinical research where clinical academics know participants as clients and as research subjects over the longer term. Support for research teams engaged in clinical research should be considered.

10.7 Limitations

10.7.1 Small sample size

This research study recruited 15 children and young people. Although this is a small number of participants, the methodology used meant that a large amount of data was collected on each case. There was a broad range of personal factors such as age, age at injury and time since injury and so it was still possible to address all of the objectives in the study.

10.7.2 **Single researcher and single centre**

This research study was carried out by a single researcher and most of the children were recruited from a residential rehabilitation centre. The benefit of having a single researcher is that there is one person who has an overview of all of the data. Furthermore there is added consistency in the delivery and collection of all data, the structure and delivery of interviews and a relationship between the researcher and the children and families can be established. Further studies would be enhanced if carried out by a research team that included a neuropsychologist. Current neuropsychological profiles were not available in this data set and may be useful in future study in order to gain further understanding of the self-awareness construct. All the children and young people in the study had been exposed to some brain injury education including information about the structure and function of the brain. In a future study children and young people who have had education could be compared to other groups who had different post-injury experiences.

10.7.3 **Measures and study design**

Not all of the measures had strong normative data and not all of the measures had been tested for cultural specificity. While developmental trends could be assessed, there was less quantitative data than expected. A simple criterion of discrepancy was used in Chapter 6 to describe each domain of each case. Discrepancy was assigned to each case when the child/young person did not endorse difficulties reported by others or if their self-report fell below the norm. The data were descriptive and the numerical values did not represent any degree of discrepancy. This limited the quantitative element of the mixed method research. It was

beneficial only as a means to distinguish those participants who had a discrepancy, albeit simple, in many domains from those who had discrepancy in only a few domains. This simple method of distinguishing discrepancy and therefore defining lack of self-awareness is common in the adult literature, but is not without flaw. There is a possibility of Type I error. There may be other reasons for a child to over or under report their difficulties compared to other adults. Parents may not witness the difficulties that a child has at school; and a non-verbal child may not report speaking as a problem if they are proficient at communicating using an alternative device. These discrepancies are therefore not as a result of lack of self-awareness.

The case study design accommodated a more descriptive approach and the cases had in-depth and rich data, which allowed self-awareness following a brain injury in childhood to be described in as full a way as possible. This was particularly the case when the qualitative data, such as the comparison to the Harter pen portraits, were combined with the quantitative data.

The study design of this initial exploratory study accommodated much of the "multimethod, multi-informant approach that considers multiple context" (Lee, 2012) that is supported for assessing the complex issue of self-awareness, and further data may have added to the researcher burden.

10.7.4 Lack of final comparative data

The data in this study indicated that children/young people identified more areas of difficulty over time. Although the later data could be compared to the developmental norms, where available, there was not a second set of parent or teacher information. A final assessment of self-other discrepancy was unfortunately not possible. This should be addressed in further studies while not causing additional burden to the families.

10.7.5 **Attrition**

It was unfortunate that some of the cases were lost to follow up as the study numbers were reduced and longitudinal data was not available for all children/young people. In most cases no explanation was given. There was one case where the young person felt that he had talked about his brain injury enough and wanted to "move on". Difficulty accessing young people for follow up should be considered in future studies and extra measures should be put in place such as greater communication between research visits.

10.8 Future recommendations

10.8.1 Future research

Some thoughts of future research have been mentioned throughout this discussion chapter. Firstly and fundamentally, more studies of self-awareness following a brain injury with larger cohorts are required. The findings in this exploratory study are tentative, but seem to indicate elements that are important in the future development of theory of self-awareness following a brain injury in childhood. These factors are outlined earlier in this chapter (see section 10.2.1) and include knowledge, the ability to reflect, the importance of context and the ability to make future plans. These suggestions come from illustrations within the data. However, theory development is at an early stage in the area of interrupted development following a brain injury in childhood, and further data driven and theory driven longitudinal research is indicated to formulate and test theoretical proposals. In addition, in-depth, qualitative studies are required to examine the complexities of the dynamic construct of self-awareness for children, young people and their families following TBI.

Secondly, this study has highlighted the need to develop measures that will capture the level of self-awareness following TBI. Self-awareness is a complex construct that will require the use of more than one measure. Following the earlier theoretical discussion, the use of three measures is suggested. These measures would include the creation of one new developmental measure, and the further development of two existing measures. Firstly, a new developmental measure of self-awareness is

required, that takes into account the variability in typical development. Secondly, the KIC and The Children's Cooking Task are recommended with further development of their psychometric properties.

10.8.2 Future clinical developments

Further clinical developments are necessary to create age-adjusted intervention resources. Brain injury education programmes for children following a brain injury should take into account the developmental issues raised in this thesis. Resources are required that accommodate the newly acquired developmental needs of children and young people. A range of resources are indicated that should not only reflect the development of self-awareness trajectory but also be age-appropriate for an older child who is functioning at a younger age level. The suggestion of a new developmental framework of self-awareness in this chapter could be used to establish the needs of the children/young people at different stages. Such a framework will help clinicians to acknowledge all of the learning and development that would have taken place pre-injury, while at the same time ensuring that they do not have expectations beyond that expected of typically developing children. Subsequently, age-adjusted intervention approaches could be developed, that would be appropriate at the different levels of self-awareness development and recovery.

Such programmes could be available for early rehabilitation services as well as later community services to support children and young people over a prolonged period of development and adjustment.

11 Conclusion

This thesis opened with two comments:

> "Children first and head-injured second" (Oddy 1993, p.314)
>
> "Children are not short adults" (Ylvisaker 1998, p.6)

Although this research has been shaped by their sentiments, the results of this study have led to an understanding of self-awareness following a brain injury in childhood that broadens the generic nature of these authors' comments.

The aim of this study has been:

> To gather quantitative and qualitative longitudinal data from children and young people who have experienced a moderate to severe traumatic brain injury in order to understand their level of self-awareness.

This study has met its intended aim, and has in fact exceeded its potential reach. While the intention was to inform clinical practice, I believe this albeit small study has gone further. The developmental perspective of this study has been endorsed, and suggestions towards a new conceptual framework and definition have been presented. These theoretical concepts will influence the study of the interrupted development of children following a brain injury in the future.

The data in this study informs clinicians that children and young people have an interrupted development of self-awareness following a moderate/severe traumatic brain injury affecting all functional domains.

Measuring self-awareness in children is different to adults, as the degree of self-awareness deficit can be evaluated in more than one way. In addition to measuring their self-report against the report from significant others, it can also be measured against that expected of typically developing children. The results of this study reported evidence of discrepancy not only when compared to the report of others, but also when compared to the normative data. Given the combined evidence from the thematic analysis and the discrepancy data in this study, it appears illogical to continue to rely on the findings of adult literature. A new measure of the developmental level of self-awareness is required,. The psychometric properties of the Knowledge Interview for Children and The Childrens Cooking Task would benefit from further development, for use in clinical practice and research.

The data in this study indicated that the degree of self-awareness deficit was primarily related to age, with the younger children having the greatest degree of discrepancy. Furthermore the study determined that the self-awareness of deficits was not an all or nothing concept, with many of the children and young people having some awareness in some of the domains. Although the development of self-awareness appeared to be interrupted in this group, it was not arrested and some of the children/young people made ongoing changes to an age appropriate level in some domains. So it is imperative that clinicians working with children following a brain injury consider their age at injury as a starting place, whilst appreciating their age-matched abilities in some aspects of the complex presentation of self-awareness.

Although we still need to know more about the relationship between self-awareness, goal setting and rehabilitation outcomes in children, it appears from this study that children have varied levels of awareness across functional domains. Occupational therapists are well positioned to use their understanding of child development and the impact of interrupted development, to work collaboratively with children and young people towards meaningful goal setting following a brain injury.

Data from this study suggest that the context of everyday occupational performance is supportive of greater self-awareness. Occupational therapists work alongside clients in the functional setting, and in line with current trends for ecological validity in assessment and intervention, it is vital that they maximise all of their everyday opportunities. They must ensure that they use the ecologically valid settings such as school and home to help children and young people benefit from feedback in familiar environments. When children and young people can more accurately assess their own performance, they may be in a better position to set realistic rehabilitation goals.

While this study has only explored one aspect of brain injury, there is a wider message for paediatric neurorehabilitation. In the field of children's brain injury and perhaps in other fields there has been an over reliance on the findings of adult studies. It is crucial that clinical and academic professionals alike in children's

neurorehabilitation appreciate the importance of child development and strive for a comprehensive evidence base that is truly child-centred.

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13 Appendices

13.1 Appendix 1: Literature review (Wales et al., 2013)

How an occupational therapist should conceptualise self-awareness following traumatic brain injury in childhood — a literature review

Lorna Wales,[1] Carol Hawley[2] and Peter Sidebotham[3]

Key words:
Self-awareness, children, brain injury.

Introduction: The development of self-awareness across childhood is a complex and protracted phenomenon. Little is known about the consequences of an interruption to development as a result of a traumatic brain injury in childhood. The aim of this paper was to review the available literature on self-awareness in children following a traumatic brain injury and relate the findings to occupational therapy practice with this group of children and young people.

Method: A comprehensive search of the current literature relating to self-awareness following a traumatic brain injury.

Findings: A small amount of theoretical and qualitative literature was sourced and critically appraised using appropriate tools. Although only nine relevant papers were identified, those that were evaluated were found to be of a high quality. The findings were supplemented with additional material from developmental psychology and adult brain injury literature.

Conclusion: Occupational therapists are encouraged to conceptualise self-awareness in childhood traumatic brain injury within a developmental context. A fuller understanding of self-awareness in childhood and the consequences of an interruption to its development will help to establish age-appropriate interventions.

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Introduction

A brain injury can occur at any time across the lifespan and can have a devastating and long-lasting effect on victims and their families (Anderson and Catroppa 2006). The number of children who sustain a head injury each year is significant and it remains the major cause of death and disability among children and young people in the United Kingdom (UK) (Sharples et al 1990, Thornhill et al 2000). The causes of traumatic brain injury (TBI) vary across the lifespan. Falls, including being dropped, and non-accidental injuries are particularly common in younger children, whereas road traffic incidents are more common in older children and teenagers (Hawley et al 2003).

There are a number of significant long-term sequelae following a TBI, which include physical, language, social, cognitive and behavioural deficits (Anderson and Catroppa 2006). The frontal lobe is particularly susceptible to damage due to the mechanical forces of an acceleration/deceleration injury. Neuropsychological consequences may result from such an injury and include deficits in self-awareness (Stuss and Anderson 2004), an issue that receives much attention in the adult brain injury literature where impaired self-awareness is cited as one of the major negative influences on long-term adult outcomes (Hart et al 2009). Impaired self-awareness is a key issue because

it leads to poor engagement in rehabilitation; individuals remain resistant to using strategies and supports in their everyday lives (Livengood et al 2010, Dirette 2010). The importance of impaired self-awareness in rehabilitation for children following TBI is unknown; however, we hypothesise that the impact on the developing brain would be even greater than in adults. It is, therefore, surprising that this issue has not received a higher profile in the children's brain injury literature.

Self-awareness is a complex and multifaceted concept and, although theories and models are available for the adult brain injury population (Crosson et al 1989, Toglia and Kirk 2000), it is not possible to make a direct transfer of knowledge from adults to children. Knowledge from child development informs us that development of self follows a protracted course and is not complete and integrated until early adulthood (Harter 1999). We also learn that the development of self in childhood is affected by a number of factors. Firstly, cognitive development has a key influence on the ability and capacity of a child to construct a continuous sense of self over time. The increasing cognitive ability of the child enables them to compare and evaluate their abilities in a number of different circumstances. Initially, younger children describe themselves in very concrete and physical terms: for example, 'I'm a boy, and I'm really big'. Younger children also tend to overestimate their abilities: for example, 'look how high I can jump — right up to the sky!'. With time, the older child can make comparisons against others' abilities: for instance, how many sums he or she has completed in a test or sporting ability compared to others. However, the adolescent has more of a turbulent time of it when trying to integrate all the different aspects of self into a whole: for instance, finding it difficult reconcile his or her ability to be kind and considerate to friends, on the one hand, while being sarcastic and unhelpful in the home on the other.

Cognition has a significant impact on development, alongside social, environmental and biological factors that influence the integrated sense of self that develops throughout childhood (Sigelman and Rider 2003). Aspects of the child's personality, cultural influences, health, family structure, sibling relationships and social influences also play a part in the way that self develops on an individual basis. Additionally, styles of parenting and teaching are crucial in providing feedback to the young person's developing sense of self but can be positive or negative, and include the impact of abuse and emotional neglect (Hildyard and Wolfe 2002, Margolin and Gordis 2000). Development of self-awareness is a dynamic process that changes along with other aspects of physical, social, cognitive and emotional development. The complexity of the development of self and its constantly changing nature highlights the possibility that it may not be appropriate to apply our knowledge of adults to children with a brain injury.

In the adult literature, individuals who have impaired self-awareness are defined as having difficulty 'understanding that they have deficits, anticipating the impact of those deficits on function and assessing their occupational performance in relation to those deficits' (Dirette et al 2008, p44). This definition highlights the importance of self-awareness to occupational therapy practice, which has occupational performance and functional ability at its core (College of Occupational Therapists 2009). Self-awareness is an equally important element of childhood occupations because, in order to achieve a meaningful occupation, there has to be a balance between the challenge of the activity and the skills of the individual (Law 2010). In the children's setting, it is the adults around the child who initially create situations to make occupations meaningful. Over time, the child acquires a history of 'doing' that informs what they might choose to do in the future and becomes aware of the capacities that they might have (Hocking 2008). It is reasonable to infer that children and young people with an impaired ability to evaluate their capacities, following a TBI, may require additional support to set realistic occupational goals and to evaluate the outcome of their performance. A deficit in goal setting and evaluation, depending on age, may restrict the child's willingness to adopt strategies in their everyday life and may lead to restrictions in their participation in the school and community setting. Children and young people may make inappropriate choices of activities that do not match their competencies, and may have lower self-esteem or participate in more risk-taking activity than typically expected during adolescence.

Occupational therapists need to understand the impact that a brain injury at different ages in childhood can have on self-awareness to be able to support children through the rehabilitation and reintegration phases of their recovery. The main aim of this paper was to review the available literature on self-awareness in children following a TBI, with the further objective of considering the relevance of the findings for occupational therapy practice in this area.

Method

Search strategy

The initial literature research strategy involved accessing online medical library search databases: Ovid Medline, CINAHL (Cumulative Index to Nursing and Allied Health), EMBASE, AMED PsycInfo and the Cochrane Database.

Table 1 shows the terms chosen for an initial literature search. Searches were limited to articles in English and with the age category 'children'. No limit was set for year of publication.

A further search strategy was used to supplement the literature published in academic journals. Textbooks on child development were accessed to obtain a range of additional terms that could be used to search the literature. Awareness of deficits is not a developmental construct, so is not generally found in child development textbooks. Instead, the concept of performance is described in terms of competency and a child's rating of their performance is described in terms of perceived competence. Key authors were noted and electronic searches of these additional terms, of authors and their assessments were made.

Table 1. Terms for initial literature search with inclusion and exclusion criteria, showing 'wildcard' options

Concept 1: impaired self-awareness	Concept 2: age range	Concept 3: traumatic brain injury
Self-awareness	Child*	brain injur*
Self-awareness	P?ediatric	traumatic brain injur*
Insight		TBI
Impaired self-awareness		
ISA		
Inclusion criteria:		
	Articles with full text available in English.	
	A focus on brain injury in childhood.	
	Addressing the concept of impaired self-awareness as the main issue.	
Exclusion criteria:		
	Adult studies.	
	Studies where the abstract refers to the reader gaining insight into, or gaining awareness of, an unrelated issue: for example, diabetes management.	

Metacognition is a term that describes knowledge of cognition and is closely related to self-awareness. Consciousness and the role of self consciousness in the development of self-awareness also emerged as an issue in the developmental psychology text. Therefore, these search terms were used and literature relating to these concepts was also accessed. This additional supporting literature was used to contribute to the discussion section of this review.

Data analysis

As the data were likely to be primarily qualitative, the key themes were established from reading and evaluating the literature. The Critical Review Forms, developed at McMaster University to assist in appraising qualitative and quantitative studies, were used to critically appraise the literature (Letts et al 2007). As part of the exercise, the researcher became very familiar with the articles, sorting them according to their methodology or their area of clinical practice. Each paper was evaluated and assigned a level of evidence using the levels described by Cesario et al (2002). There are three levels of evidence (QI-QIII) where QI indicates a high-level, well-constructed qualitative study.

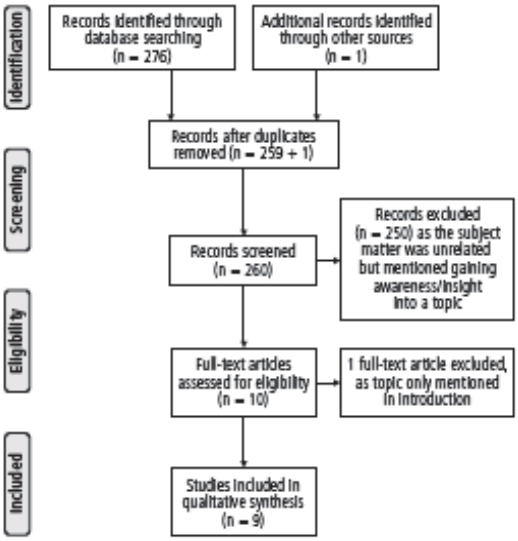
This author prefers a visual representation of information, and a data display in the form of a mind map was used to link and synthesise ideas (Miles and Huberman 1994). Literature was reviewed to establish similar concepts and examine concepts where they differed. While greater confidence was placed in emerging ideas that were similar and replicable, findings that differed were considered of equal significance because new understandings are still being constructed in this developing area (Huberman and Miles 2002).

Findings

The search yielded 276 articles. An additional article was sourced from an information booklet at a brain injury conference. The titles and abstracts of these articles were screened using the inclusion/exclusion criteria.

The adult literature yielded two further articles where there were teenagers/adolescents in the sample population (see Fig. 1).

*Fig. 1. Flow diagram identifying studies.**



*Using the PRISMA 2009 flowchart for undertaking systematic reviews and meta-analysis (www.prisma-statement.org).

Full texts were acquired in these ten additional cases and all were read and evaluated. One paper was rejected because the specificity of the topic area had limited clinical utility to occupational therapists working in the field of brain injury in childhood (Newsome et al 2010).

The remaining studies (n = 9) were classified initially by methodology. There were three papers that addressed theory and guidelines for practice, two case studies, three case-control studies and one experimental study. Six of the studies were qualitative in nature and were evaluated and assigned a level of evidence as described by Cesario et al (2002); all six (Jacobs 1993, Beardmore et al 1999, Josman et al 2000, Josman and Jarus 2001, Viguer et al 2001, Zlotnic et al 2009) were classified as QI studies. See Table 2 for a summary of evidence.

Three main themes emerged from the literature search: theory building and guidelines for practice regarding self-awareness following TBI in childhood; assessment of children following TBI and interventions to improve self-awareness following TBI in childhood.

Theory building

Three papers focus on theory building and guidelines for practice regarding self-awareness following TBI in childhood. Assigning levels of evidence to this literature is not appropriate. However, it is appropriate to appraise them within the context of the Medical Research Council (MRC) guidelines for developing and evaluating complex interventions (Medical Research Council 2008). This robust framework has been revised to incorporate a more dynamic approach to evaluating theory building, which is no longer viewed as a first and pre-clinical stage of emerging evidence. Emerging theory should be reviewed and revised to link to emerging research. Three theory papers were sourced in this literature review, each written by experienced, well-respected researchers writing within the context of other relevant theory and demonstrating sound knowledge of the clinical and academic issues. The papers incorporated case studies and neuroscience/neuropsychological concepts and made reference to adult and developmental perspectives; all three papers were considered to be of a high quality.

In two of the papers the authors started with the premise of adult models (Marcantuono and Prigatano 2008, Gracey et al 2010) and conceptualised their utility with a younger population. Marcantuono and Prigatano (2008) utilized the holistic brain injury rehabilitation program (Ben-Yishay and Diller 1990) while Gracey et al (2010) applied the holistic neuropsychological rehabilitation model (Cicerone et al 2006). In both cases the focus of the theoretical model was on adjustment and adaptation following traumatic brain injury. The authors made adaptations to these adult models

Table 2. Article summary table

Study	Methods	Subjects	Findings	Level of evidence
Limited understanding of deficit in children with brain dysfunction (Jacobs 1993)	Exploratory multiple case study	n = 10, age 7-15 years	All children had limited understanding of their condition with more awareness of physical aspects of disability.	QI
Does information and feedback improve children's knowledge and awareness of deficits after traumatic brain injury (Beardmore et al 1999)	Experimental	n = 21, age 9-16 years	Subjects had poor understanding of TBI and some had unawareness of deficits but not helped by intervention programme.	QI
Performance of children with and without TBI on the contextual memory test (Josman et al 2000)	Case control	n = 30, age 8-14 years, severe TBI + 30 controls	Brain injury group scored lower in memory assessment. Self-awareness scores correlated to performance scores.	QI
Evaluating categorization skills in children following severe brain injury (Josman and Jarus 2001)	Case control	n = 60; severe TBI = 30 and non-TBI = 30, age 8-14 years	Brain injury group scored lower in cognitive assessment. Self-awareness scores correlated to performance scores.	QI
A psychological assessment of adolescent and young adult inpatients after traumatic brain injury (Viguier et al 2001)	Case control	n = 186; TBI = 83 and non-TBI = 103, age 14-25 years	Different levels of awareness in different domains. Poorer self-awareness in cognitive and behavioural domains. Also explored relationship between self-awareness and anxiety/depression.	QI
Use of the dynamic interactional model in self care and motor intervention after traumatic brain injury: explanatory case studies (Zlotnic et al 2009)	Case study	n = 2, age 16, 17 years	Improved awareness in mobility and writing domains following Toglia adult model of intervention (Toglia and Kirk 2000).	QI
The frontal lobes and theory of mind: developmental concepts from adult focal lesion research (Stuss and Anderson 2004)	Theory	n/a	Proposition of a hierarchical model of consciousness that includes injury and developmental influences.	n/a
A holistic brain injury rehabilitation program for school-age children (Marcantuono and Prigatano 2008)	Guidelines for practice	n/a	Proposition of a multidisciplinary programme of intervention with the explicit aim of developing awareness of deficits.	n/a
Holistic rehabilitation in the developmental context (Gracey et al 2010)	Guidelines for practice	n/a	Proposition of an integrated model of psychosocial adjustment and development following acquired brain injury.	n/a

to accommodate the unique differences in childhood. Marcantuono and Prigatano (2008) stressed that children are developing self-identity at the time of an injury and require particular guidance in order to develop a realistic view of who they are and how the injury may have affected them. The authors echoed the point that it is not until individuals reach adulthood that self-identity becomes fully established, and also promoted the use of less complex language, increased therapeutic support and the setting of age-appropriate goals.

In the third paper, Stuss and Anderson (2004) acknowledged the unique differences in childhood, from the perspective of biological change and skills development as well as a psychological standpoint. The hierarchical model proposed by Stuss et al (2001), which was summarised in this paper, focuses on brain regions and in particular on the frontal lobes. Stuss and Anderson (2004) considered the biological maturation of the brain and reflected that regional areas may not be as hard wired in the immature brain. The authors proposed that it may be more beneficial to provide a more integrated conceptualization of adult and child theory and consequently promoted a comprehensive framework that might inform future research.

As with the adult literature, two authors highlighted the domain specificity of self-awareness: that is, having more awareness of physical than other deficits (Jacobs 1993, Viguier et al 2001) and acknowledged the complexity and multifaceted nature of self-awareness in childhood.

Assessments

Only one assessment of self-awareness for children was identified in the literature review (Beardmore et al 1999). The Knowledge Interview for Children (KIC) was developed from the findings of a previous study that highlighted the lack of knowledge that children with TBI have about their injury. This small study used the KIC to measure change in self-awareness following an intervention programme.

In one of the intervention papers, the authors described a mobility awareness measure designed for the purposes of the study, but little information was available within the paper or through further searching (Zlotnic et al 2009).

Interventions

In parallel with the guidelines for practice papers, Zlotnic et al (2009) also utilized an adult model of self-awareness (Toglia 2005) in an intervention setting. Two case studies were presented in relation to the dynamic interaction model of self-awareness. Joint goals were set and self-awareness training included direct feedback, encouraging self-evaluation, providing cues and discussing situations when deficits may interfere with functional performance. At times the feedback was concrete and focused on motor activities (as in case 2). Self rating and therapist ratings were compared throughout the programme.

One small experimental study of self-awareness following TBI in children was identified in the literature (Beardmore et al 1999) and rated as level Q1 evidence. Children with TBI were assigned to two groups of injury education or study skills information sessions. The findings were limited due to the small sample size and the short-term nature of the intervention and review programme. In addition, one of the clinical guidance papers suggested that the intervention package of the adult model could be utilized with a population of children following a brain injury (Marcantuono and Prigatano 2008). There was a thread running through the proposed rehabilitation programme that included the use of feedback and structured explicit support towards a key goal of increasing self-awareness.

Discussion and implications

This literature review yielded a disappointing number of articles relating to this potentially important area of occupational therapy practice. However, it was encouraging that the quality of the evidence was high when evaluated using a tool developed to appraise qualitative studies (Cesario et al 2002). From a theoretical perspective, clinicians working with children and young people following TBI have little information to guide their practice and are tempted to rely on the adult literature. Some authors had attempted to increase the evidence base by using an adult model and considering its utility with a younger age group (Marcantuono and Prigatano 2008, Gracey et al 2010). In the earlier case, the authors acknowledged this was not an ideal situation; young people are still in a period of development when they sustain the injury so may not be directly comparable to the adult population. Other authors proposed a preferable situation that integrated adult and child theory in order to increase understanding of the complexity of impaired self-awareness following a brain injury in childhood (Stuss and Anderson 2004). A step further would be to carry out empirical research with knowledge of child development at its core in order to build new theoretical frameworks from the perspective of childhood.

Key texts by Harter (1999) and Damon and Hart (1988) contained clear descriptions of the development of self in childhood. These three individuals were among many authors who referenced the early work of the philosopher, William James. James outlined a concept of self that provided the framework for these later researchers. He described two aspects of self — the 'I' self and the 'me' self — which relate to the actual qualities of the material, social and spiritual self. He also explored the awareness of the self and its sense of agency, continuity and distinctiveness (James 1890). All of these aspects of self-awareness change over time but, for James, not in a staged manner — thus, differing from other developmental theorists such as Piaget (Miller 2011). In James's model, the child may mature in different domains at different rates; unlike staged theories, there is no loss of previous performance when the individual has the ability to access the next stage of maturity.

The authors of these papers presented visual hierarchical models within their texts that were very accessible. They

showed the changes that occur from younger to older children within the different self domains: from changes in physical self from bodily properties or material possessions in early childhood to physical attributes reflecting volitional choices, or personal and moral standards in late adolescence (Damon and Hart 1988). Harter also used pen portraits to describe children of certain ages, which very clearly showed the changes over time (Harter 1999). For example, the author described the young child who is overly positive about their abilities while, however, describing physical attributes and characteristics in a very concrete manner:

> I can also throw a ball real far, I'm going to be on some kind of team when I'm older. I can do lots of stuff real good. Lots! (Harter 1999, p41).

Instruments for the measurement of self in childhood were presented in these key texts: the Self-Perception Profile for Children (SPPC) (Harter 2012a), a self-report measure that taps five specific domains: scholastic competence, athletic competence, social acceptance, physical appearance and behavioural conduct, with a separate upward extension for adolescents (Harter 2012b) and a downward extension for younger children, containing illustrations (Harter and Pike 1984); the Self-understanding Interview (Damon and Hart 1988), a semi-structured interview with seven main questions concerning different aspects of self (among them self-definition, self-evaluation, self in past and future, self interest, continuity, agency and distinctness), each containing further probe questions to encourage elaboration.

These instruments continue to be referenced in the children's literature, in both educational and clinical settings, and may be useful for occupational therapists and their psychology colleagues to consider. While, unfortunately, neither has been validated for a brain injury population they may provide therapists with an indication of the developmental stage at which their client is operating and could be used alongside the KIC, the latter specifically developed for this population (Beardmore et al 1999). Alongside other cognitive assessments, the clinician could use the results to tailor intervention. For example, as suggested by other authors, the clinician could give feedback in a very simple, supportive and concrete manner (Marcantuono and Prigatano 2008). An affected child, regardless of age, might find it difficult to conceptualise social sequelae of their brain injury, and the impact of these on future friendships, until they have more sophisticated self-development and neurodevelopment. The frontal lobes develop slowly over the course of childhood, with a burst of neural development in adolescence. Children at an earlier stage lack the metacognitive capacity to evaluate more abstract concepts, such as social and behavioural competencies. If a child has a TBI during this critical period of frontal lobe development, there may be an impact on skills such as self-awareness (Stuss and Anderson 2004).

Just as children's occupational therapists are confident of the developmental milestones in children's occupations, they could also become familiar with the milestones associated with the development of self-awareness. Just as an occupational therapist would not endeavour, for instance, to teach complex cookery skills to a younger child, intervention related to self-awareness must also be led by the norms of developing self in the typical population. As described by Harter, middle childhood is a time when the child can begin to make more comparative judgements:

> At school, I'm feeling pretty smart in certain subjects like Language, Arts and Social Studies. I got A's in these subjects on my last report card and was really proud of myself. But I'm feeling pretty dumb in Math and Science, especially when I see how well a lot of the other kids are doing (Harter 1999, p48).

It may be that the child in the example above is able to engage with the therapist in simple comparisons of present and past performance. So far, there is insufficient evidence to support the use of the interventions and strategies used for adults with impaired self-awareness within children's occupational therapy. However, evidence in the adult literature promotes the use of previously mastered occupations to enable a more successful review of performance by individuals following TBI (Dirette et al 2008). Such feedback that promotes comparison but is focused around occupations may be indicated for children with this level of self development.

Reduced self-awareness in adults has an impact both on engagement in rehabilitation and goal setting (Hart et al 2009) but there is little evidence from the literature to support the same observation regarding children and young people who have sustained a TBI. Given the paucity of supporting evidence, the researcher hypothesises that comparable poor outcomes, to which a lack of awareness in children may lead, could include reduced success at school and difficulty sustaining friendships. For example, the young person may not appreciate the need to integrate strategies into everyday life and may not understand the impact of subtle social communication deficits. These events may be the beginning of a chain of events that causes the young person to disengage and make alternative lifestyle choices. There is, for instance, emerging evidence of a significant number of individuals in the prison population who have sustained an earlier TBI in childhood (Williams et al 2010). The occupational therapist has to be diligent in recognising the, often subtle and high-level, difficulties following brain injury in order to provide age-appropriate support to the young person who is identifying these deficits for themselves.

It is encouraging that Tonks et al (2009) provided an excellent worked example of how a developmentally driven approach can be applied to one particular area — emotion and empathy skills — following brain injury in childhood. The key to the success of this work was that the authors explicitly set out to explore social competence as it develops in childhood and the manner in which the expression and/or development of skills will be affected by brain injury. The authors highlighted the importance of taking a temporal perspective in childhood — that is, the change over time — and considering the maturation of children from a physiological, as well as a cognitive and social, dimension. An

integrated approach of this kind would benefit further research in this important area of self-awareness in brain injury rehabilitation in children.

Conclusion

This critical review found insufficient direct evidence from the literature to guide occupational therapy practice in the area of self-awareness following TBI in childhood. In particular, there was little direct evidence about addressing self-awareness at different ages and a lack of description of how self-awareness changes over time — understanding these changes is critical for assessing any impairments in self-awareness following TBI in children.

However, the quality of the limited evidence available was high and, when combined with other supporting evidence from developmental psychology texts, enables occupational therapists to gain an understanding of the development of self-awareness across childhood. Some key components of the development of self-awareness include: a shift from a focus on concrete, physical attributes to the consideration of volitional and moral influences; the ability of children to make comparative judgments and the role of agency, continuity and distinctiveness. Harter (1999) and Damon and Hart (1988) are recommended for occupational therapists wanting to gain more understanding of self-awareness in childhood as accessible texts that clearly describe typical self-descriptions. Both authors have developed accompanying assessment measures that are widely used with typically developing children and could be considered for their utility in children following brain injury.

Taking a developmental perspective allows the occupational therapist to re-evaluate the adult brain injury evidence for children of different ages. Occupational therapists will then be in a position to consider the types of assessments and interventions that would be appropriate to use when working with children and young people following TBI. This newly integrated knowledge of the typical developmental progression of self-awareness is crucial for occupational therapists when setting child-focused goals for children and young people of all ages. Future research should investigate the appropriateness of this integrated approach for further understanding the impact of a brain injury on the development of self-awareness in childhood.

Key findings

- Literature directly relating to impaired self-awareness following TBI in childhood is sparse.
- Occupational therapists are encouraged to conceptualise impaired self-awareness within a developmental context.

What the study has added

This review prompts occupational therapists to reconsider their conceptualisation of impaired self-awareness following a TBI in childhood in order to adopt a more age-appropriate approach to their interventions.

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13.2 Appendix 2: Letter of introduction

Dear _____

The Children's Trust is committed to an ongoing research programme. We are keen to understand more about the effects of a brain injury on children and their families. As part of this programme one of our staff members is planning a research study. It will involve all children who have had a Traumatic Brain Injury and have used the services of The Children's Trust in the last 5 years.

Lorna Wales is a clinical specialist occupational therapist and she is planning to investigate how a brain injury can affect self-awareness in children.

Lorna plans to contact you shortly to discuss the project more fully and to provide you with written information about the details of the study.

If you do not wish to be approached about this research study, please let me know using the contact details below.

Thank you in anticipation.

Yours Sincerely

Andrew Ross
Chief Executive
Telephone: 01737 365000
e-mail: aross@thechildrenstrust.org.uk

13.3 Appendix 3: Letter of invitation

Date

Dear

My name is Lorna Wales. I am an occupational therapist at The Children's Trust and I am carrying out a research study to investigate the development of self-awareness in children following a brain injury as part of a PhD course of study. I would like to invite you to take part in the study. Before agreeing to take part, I would like to provide you with some more information. I have attached an information sheet for you and your child.

If you feel able to take part in the study I would invite you to sign the consent form attached and return to me in the stamped addressed envelope in the next 7 days. Alternatively, the consent can be signed during my initial visit to give you and your child the opportunity to ask questions.

Yours sincerely

Lorna Wales MScDipCOT

13.4 Appendix 4: Sample of information letter (11+ years)

Information about the research

Study title Self-awareness following a brain injury in childhood

Introduction I am asking if you would join in a research study to find the answer to the question of how a brain injury can affect how children of different ages see themselves.

Before you decide if you want to join in, it's important to understand why the research is being done and what it will involve for you. So please consider this leaflet carefully. Talk to your family, friends, doctor or nurse if you want to.

(Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study).

PART 1

Why am I doing the research? The aim of the study is to improve clinicians understanding of the impact of a moderate to severe traumatic brain injury on the development of self-awareness in childhood in order for them to set age appropriate rehabilitation goals. The study will try to find out how a Traumatic Brain Injury (TBI) can affect the way that children of different ages see themselves in the years after their injury. It will help professionals, such as therapists understand how children feel.

Why have I been invited to take part? You have been chosen for this study because you had a traumatic brain injury (TBI). This project will involve 20 children.

Do I have to take part? No. It is up to you. We will ask you for your assent and then ask if you would sign a form. We will give you a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the

research without giving a reason. If you decide to stop, this will not affect the care you receive.

What will happen to me if I take part? You will be asked to fill in 1 or 2 questionnaires, depending how old you are. They will have about 30 questions on them and will take about 30 minutes. You can write the answers yourself or I can help. I will also ask you questions in an interview that will take about 45 minutes. I will tape the interview and then type up what you said afterwards. Your parents and teacher will also be asked to fill in some of the questionnaires.

The study will run for 2 years and I will visit 4 times in all – every 6 months. I will only do the interview on 3 of the visits but you will fill in the forms 4 times.

What will I be asked to do? You will have to stay in the study for the 2 years and complete all the measures at each visit.

Is there anything to worry about if I take part? There is a small risk to being in this study. Talking about personal experiences can sometimes be upsetting. So we can stop the interview at any time if you are getting upset. We will let your parents know so that they can be supportive and we can alert professional colleagues if there are issues that need further support.

What are the possible benefits of taking part? We cannot promise that the study will help you but the information we get from this study will help improve the treatment of children who have had a brain injury. We hope that professionals, such as therapists and teachers will be able to help children and young people more in the future if they understand what children of different ages go through after a brain injury.

Please contact Lorna Wales for further information, Tel:01737365874

Thank you for reading so far – if you are still interested, please go to Part 2

PART 2 More detail – information you need to know if you want to take part

What if there is a problem or something goes wrong? You must let me know as soon as you can if anything goes wrong and we will give advice. Please contact Lorna Wales, Tel: 01737365874. If you remain unhappy and wish to complain formally, you can do this. Please contact Dr Carol Hawley, Tel: 02476522459.

Will anyone else know I'm doing this? We will keep your information in confidence. This means we will only tell those who have a need or right to know. Wherever possible, we will only send out information that has your name and address removed.

Who is organising and funding the research? The research study is funded jointly by The Children's Trust and the researcher. The researcher is registered at the University of Warwick.

Who has reviewed the study? Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the Research Ethics Committee - NRES Committee London - Chelsea and Fulham.

Thank you for reading this – please ask any questions if you need to.

13.5 Appendix 5: sample of consent for (11+ years)

Study Number: 11/LO/1833
Patient Identification Number for this study: ISA1

CONSENT FORM

Title of Project: Self-awareness after brain injury in childhood
Name of Researcher: Lorna Wales

	Please initial box
1. I confirm that I have read and understand the information sheet dated 26/9/2011 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw them at any time without giving any reason, without my medical care or legal rights being affected.	☐
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from The Children's Trust and University of Warwick, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	☐
5. I agree to take part in the above study.	☐

Name of Patient Date

Signature

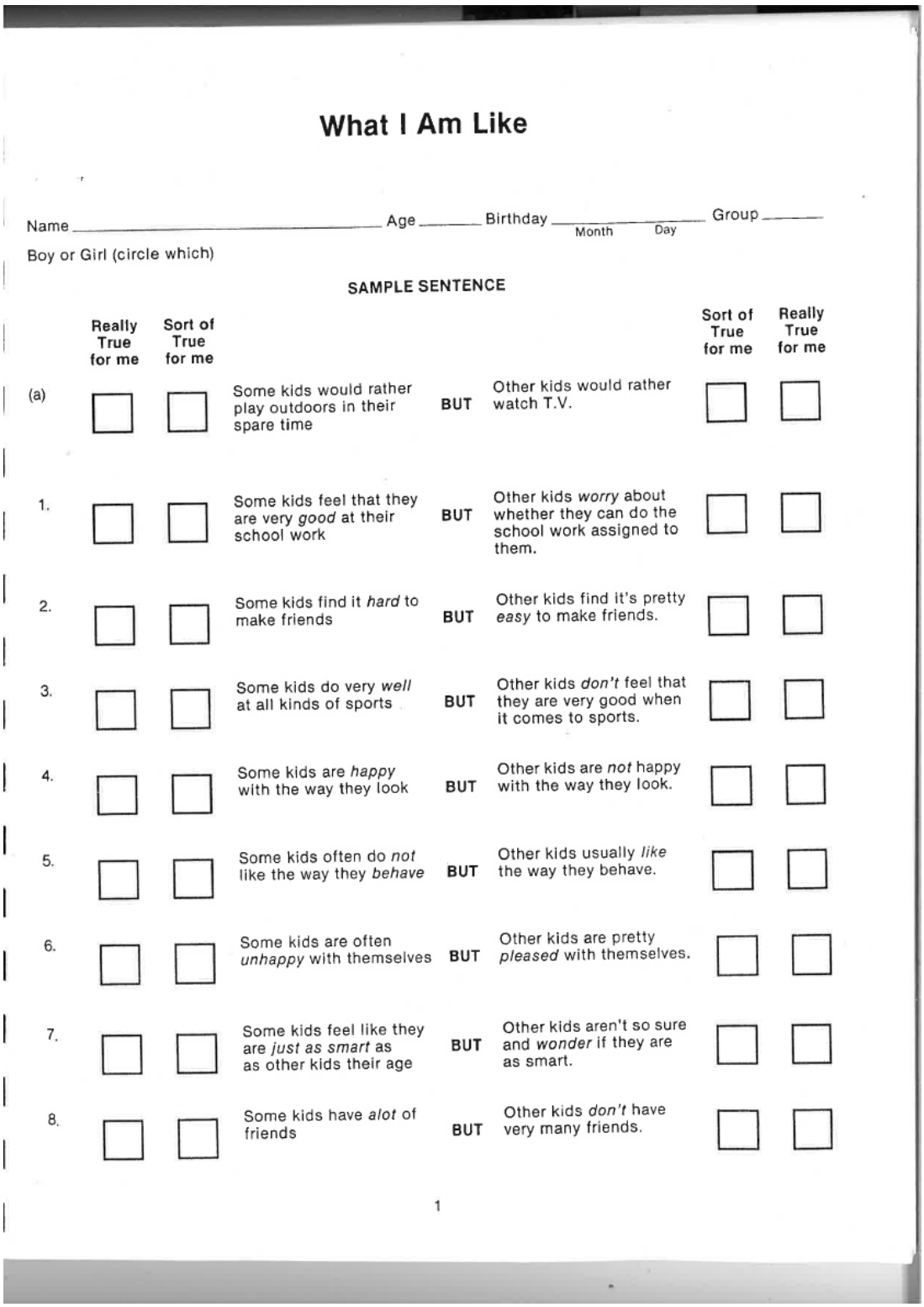
Name of Person taking consent Date

Signature

When completed: 1 for participant; 1(original) for researcher site file

13.6 Appendix 6: Harter Scales question format

13.6.1 SPPC child form



What I Am Like

Name _____ Age _____ Birthday _____ (Month / Day) Group _____

Boy or Girl (circle which)

SAMPLE SENTENCE

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
(a)	☐	☐	Some kids would rather play outdoors in their spare time	**BUT**	Other kids would rather watch T.V.	☐	☐
1.	☐	☐	Some kids feel that they are very *good* at their school work	**BUT**	Other kids *worry* about whether they can do the school work assigned to them.	☐	☐
2.	☐	☐	Some kids find it *hard* to make friends	**BUT**	Other kids find it's pretty *easy* to make friends.	☐	☐
3.	☐	☐	Some kids do very *well* at all kinds of sports	**BUT**	Other kids *don't* feel that they are very good when it comes to sports.	☐	☐
4.	☐	☐	Some kids are *happy* with the way they look	**BUT**	Other kids are *not* happy with the way they look.	☐	☐
5.	☐	☐	Some kids often do *not* like the way they *behave*	**BUT**	Other kids usually *like* the way they behave.	☐	☐
6.	☐	☐	Some kids are often *unhappy* with themselves	**BUT**	Other kids are pretty *pleased* with themselves.	☐	☐
7.	☐	☐	Some kids feel like they are *just as smart* as as other kids their age	**BUT**	Other kids aren't so sure and *wonder* if they are as smart.	☐	☐
8.	☐	☐	Some kids have *alot* of friends	**BUT**	Other kids *don't* have very many friends.	☐	☐

1

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
9.	☐	☐	Some kids wish they could be alot better at sports	**BUT**	Other kids feel they are good enough at sports.	☐	☐
10.	☐	☐	Some kids are *happy* with their height and weight	**BUT**	Other kids wish their height or weight were *different.*	☐	☐
11.	☐	☐	Some kids usually do the *right* thing	**BUT**	Other kids often *don't* do the right thing.	☐	☐
12.	☐	☐	Some kids *don't* like the way they are leading their life	**BUT**	Other kids *do* like the way they are leading their life.	☐	☐
13.	☐	☐	Some kids are pretty *slow* in finishing their school work	**BUT**	Other kids can do their school work *quickly.*	☐	☐
14.	☐	☐	Some kids would like to have alot more friends	**BUT**	Other kids have as many friends as they want.	☐	☐
15.	☐	☐	Some kids think they could do well at just about any new sports activity they haven't tried before	**BUT**	Other kids are afraid they might *not* do well at sports they haven't ever tried.	☐	☐
16.	☐	☐	Some kids wish their body was *different*	**BUT**	Other kids *like* their body the way it is.	☐	☐
17.	☐	☐	Some kids usually *act* the way they know they are *supposed* to	**BUT**	Other kids often *don't* act the way they are supposed to.	☐	☐
18.	☐	☐	Some kids are *happy* with themselves as a person	**BUT**	Other kids are often *not* happy with themselves.	☐	☐
19.	☐	☐	Some kids often *forget* what they learn	**BUT**	Other kids can remember things *easily.*	☐	☐
20.	☐	☐	Some kids are always doing things with *alot* of kids	**BUT**	Other kids usually do things *by themselves.*	☐	☐

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
21.	☐	☐	Some kids feel that they are *better* than others their age at sports	**BUT**	Other kids *don't* feel they can play as well.	☐	☐
22.	☐	☐	Some kids wish their physical appearance (how they look) was *different*	**BUT**	Other kids *like* their physical appearance the way it is.	☐	☐
23.	☐	☐	Some kids usually get in *trouble* because of things they do	**BUT**	Other kids usually *don't* do things that get them in trouble.	☐	☐
24.	☐	☐	Some kids *like* the kind of *person* they are	**BUT**	Other kids often wish they were someone else.	☐	☐
25.	☐	☐	Some kids do *very well* at their classwork	**BUT**	Other kids *don't* do very well at their classwork.	☐	☐
26.	☐	☐	Some kids wish that more people their age liked them	**BUT**	Other kids feel that most people their age *do* like them.	☐	☐
27.	☐	☐	In games and sports some kids usually *watch* instead of play	**BUT**	Other kids usually *play* rather than just watch.	☐	☐
28.	☐	☐	Some kids wish something about their face or hair looked *different*	**BUT**	Other kids *like* their face and hair the way they are.	☐	☐
29.	☐	☐	Some kids do things they know they *shouldn't* do	**BUT**	Other kids *hardly ever* do things they know they shouldn't do.	☐	☐
30.	☐	☐	Some kids are very *happy* being the way they are	**BUT**	Other kids wish they were *different*.	☐	☐
31.	☐	☐	Some kids have *trouble* figuring out the answers in school	**BUT**	Other kids almost *always* can figure out the answers.	☐	☐
32.	☐	☐	Some kids are *popular* with others their age	**BUT**	Other kids are *not* very popular.	☐	☐

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
33.	☐	☐	Some kids *don't* do well at new outdoor games	**BUT**	Other kids are *good* at new games right away.	☐	☐
34.	☐	☐	Some kids think that they are good looking	**BUT**	Other kids think that they are not very good looking.	☐	☐
35.	☐	☐	Some kids behave themselves very well	**BUT**	Other kids often find it hard to behave themselves.	☐	☐
36.	☐	☐	Some kids *are* not very happy with the way they do alot of things	**BUT**	Other kids think the way they do things is *fine*.	☐	☐

Susan Harter, Ph.D., University of Denver, 1985

13.6.2 **SPPC teacher form**

TEACHER'S RATING SCALE OF CHILD'S ACTUAL BEHAVIOR

(Parallels the self-perception profile for children)

hild's name _____ Class/grade/group _____ Rater _____

or each child, please indicate what you feel to be his/her actual competence on each question, in your opinion. First ecide what kind of child he or she is like, the one described on the left or right, and then indicate whether this is just sort f true or really true for that individual. Thus, for each item, check *one* of four boxes.

	Really True	Sort of True				Sort of True	Really True
1.	☐	☐	This child is really good at his/her school work	OR	This child can't do the school work assigned.	☐	☐
2.	☐	☐	This child finds it hard to make friends	OR	For this child it's pretty easy.	☐	☐
3.	☐	☐	This child does really well at all kinds of sports	OR	This child isn't very good when it comes to sports.	☐	☐
4.	☐	☐	This child is good-looking	OR	This child is not very good-looking.	☐	☐
5.	☐	☐	This child is usually well-behaved	OR	This child is often not well-behaved.	☐	☐
6.	☐	☐	This child often forgets what s/he learns	OR	This child can remember things easily.	☐	☐
7.	☐	☐	This child has alot of friends	OR	This child doesn't have many friends.	☐	☐
8.	☐	☐	This child is better than others his/her age at sports	OR	This child can't play as well.	☐	☐
9.	☐	☐	This child has a nice physical appearance	OR	This child doesn't have such a nice physical appearance.	☐	☐
10.	☐	☐	This child usually acts appropriately	OR	This child would be better if s/he acted differently.	☐	☐
11.	☐	☐	This child has trouble figuring out the answers in school	OR	This child almost always can figure out the answers.	☐	☐
12.	☐	☐	This child is popular with others his/her age	OR	This child is not very popular.	☐	☐
13.	☐	☐	This child doesn't do well at new outdoor games	OR	This child is good at new games right away.	☐	☐
14.	☐	☐	This child isn't very good looking	OR	This child is pretty good-looking.	☐	☐
15.	☐	☐	This child often gets in trouble because of things he/she does	OR	This child usually doesn't do things that get him/her in trouble.	☐	☐

13.6.3 **SPPA adolescent form**

SAMPLE SENTENCE

Really True for Me	Sort of True for Me				Sort of True for Me	Really True for Me
☐	☐	Some teenagers like to go to movies in their spare time	**BUT**	Other teenagers would rather go to sports events.	☐	☐
☐	☐	Some teenagers feel that they are just as smart as others their age	**BUT**	Other teenagers aren't so sure and wonder if they are as smart.	☐	☐
☐	☐	Some teenagers find it hard to make friends	**BUT**	For other teenagers it's pretty easy.	☐	☐
☐	☐	Some teenagers do very well at all kinds of sports	**BUT**	Other teenagers don't feel that they are very good when it comes to sports.	☐	☐
☐	☐	Some teenagers are *not* happy with the way they look	**BUT**	Other teenagers *are* happy with the way they look.	☐	☐
☐	☐	Some teenagers feel that they are ready to do well at a part-time job	**BUT**	Other teenagers feel that they are not quite ready to handle a part-time job.	☐	☐
☐	☐	Some teenagers feel that if they are romantically interested in someone, that person will like them back	**BUT**	Other teenagers worry that when they like someone romantically, that person *won't* like them back.	☐	☐
☐	☐	Some teenagers usually do the right thing	**BUT**	Other teenagers often don't do what they know is right.	☐	☐
☐	☐	Some teenagers are able to make really close friends	**BUT**	Other teenagers find it hard to make really close friends.	☐	☐
☐	☐	Some teenagers are often disappointed with themselves	**BUT**	Other teenagers are pretty pleased with themselves.	☐	☐
☐	☐	Some teenagers are pretty slow in finishing their school work	**BUT**	Other teenagers can do their school work more quickly.	☐	☐
☐	☐	Some teenagers have a lot of friends	**BUT**	Other teenagers don't have very many friends.	☐	☐
☐	☐	Some teenagers think they could do well at just about any new athletic activity	**BUT**	Other teenagers are afraid they might not do well at a new athletic activity.	☐	☐

Really True for Me	Sort of True for Me				Sort of True for Me	Really True for Me
☐	☐	Some teenagers wish their body was different	**BUT**	Other teenagers like their body the way it is.	☐	☐
☐	☐	Some teenagers feel that they *don't* have enough skills to do well at a job	**BUT**	Other teenagers feel that they *do* have enough skills to do a job well.	☐	☐
☐	☐	Some teenagers are *not* dating the people they are really attracted to	**BUT**	Other teenagers *are* dating those people they are attracted to.	☐	☐
☐	☐	Some teenagers often get in trouble for the things they do	**BUT**	Other teenagers usually *don't* do things that get them in trouble	☐	☐
☐	☐	Some teenagers do have a close friend they can share secrets with	**BUT**	Other teenagers do not have a really close friend they can share secrets with	☐	☐
☐	☐	Some teenagers don't like the way they are leading their life	**BUT**	Other teenagers do like the way they are leading their life.	☐	☐
☐	☐	Some teenagers do very well at their classwork	**BUT**	Other teenagers don't do very well at their classwork.	☐	☐
☐	☐	Some teenagers are very hard to like	**BUT**	Other teenagers are really easy to like.	☐	☐
☐	☐	Some teenagers feel that they are better than others their age at sports	**BUT**	Other teenagers don't feel they can play as well.	☐	☐
☐	☐	Some teenagers wish their physical appearance was different	**BUT**	Other teenagers like their physical appearance the way it is.	☐	☐
☐	☐	Some teenagers feel they are old enough to get and keep a paying job	**BUT**	Other teenagers do not feel they are old enough, yet, to really handle a job well	☐	☐
☐	☐	Some teenagers feel that people their age will be romantically attracted to them	**BUT**	Other teenagers worry about whether people their age will be attracted to them.	☐	☐
☐	☐	Some teenagers feel really good about the way they act	**BUT**	Other teenagers *don't* feel that good about the way they often act	☐	☐
☐	☐	Some teenagers wish they had a really close friend to share things with	**BUT**	Other teenagers *do* have a close friend to share things with.	☐	☐
☐	☐	Some teenagers are happy with themselves most of the time	**BUT**	Other teenagers are often not happy with themselves.	☐	☐
☐	☐	Some teenagers have trouble figuring out the answers in school	**BUT**	Other teenagers almost always can figure out the answers.	☐	☐

	Really True for Me	Sort of True for Me				Sort of True for Me	Really True for Me
29.	☐	☐	Some teenagers are popular with others their age	**BUT**	Other teenagers are not very popular.	☐	☐
30.	☐	☐	Some teenagers don't do well at new outdoor games	**BUT**	Other teenagers are good at new games right away.	☐	☐
31.	☐	☐	Some teenagers think that they are good looking	**BUT**	Other teenagers think that they are not very good looking.	☐	☐
32.	☐	☐	Some teenagers feel like they could do better at work they do for pay	**BUT**	Other teenagers feel that they are doing really well at work they do for pay.	☐	☐
33.	☐	☐	Some teenagers feel that they are fun and interesting on a date	**BUT**	Other teenagers wonder about how fun and interesting they are on a date.	☐	☐
34.	☐	☐	Some teenagers do things they know they shouldn't do	**BUT**	Other teenagers hardly ever do things they know they shouldn't do.	☐	☐
35.	☐	☐	Some teenagers find it hard to make friends they can really trust	**BUT**	Other teenagers *are* able to make close friends they can really trust.	☐	☐
36.	☐	☐	Some teenagers like the kind of person they are	**BUT**	Other teenagers often wish they were someone else.	☐	☐
37.	☐	☐	Some teenagers feel that they are pretty intelligent	**BUT**	Other teenagers question whether they are intelligent.	☐	☐
38.	☐	☐	Some teenagers feel that they are socially accepted	**BUT**	Other teenagers wished that more people their age accepted them.	☐	☐
39.	☐	☐	Some teenagers do not feel that they are very athletic	**BUT**	Other teenagers feel that they *are* very athletic.	☐	☐
40.	☐	☐	Some teenagers really like their looks	**BUT**	Other teenagers wish they looked different.	☐	☐
41.	☐	☐	Some teenagers feel that they are really able to handle the work on a paying job	**BUT**	Other teenagers wonder if they are really doing as good a job at work as they should be doing	☐	☐
42.	☐	☐	Some teenagers usually *don't* go out with the people they would really like to date	**BUT**	Other teenagers *do* go out with the people they really want to date.	☐	☐
43.	☐	☐	Some teenagers usually act the way they know they are supposed to	**BUT**	Other teenagers often don't act the way they are supposed to.	☐	☐
44.	☐	☐	Some teenagers *don't* have a friend that is close enough to share really personal thoughts with	**BUT**	Other teenagers do have a close friend that they can share personal thoughts and feelings with.	☐	☐
45.	☐	☐	Some teenagers are very happy being the way they are	**BUT**	Other teenagers wish they were different.	☐	☐

13.6.4 **SPPA teacher form**

	Really True	Sort of True				Sort of True	Really True
1.	☐	☐	This individual is intelligent	OR	This individual is not that intelligent	☐	☐
2.	☐	☐	This individual does not have a lot of friends	OR	This individual does have a lot of friends	☐	☐
3.	☐	☐	This individual is good at sports	OR	This individual is not that good at sports	☐	☐
4.	☐	☐	This individual has a nice physical appearance	OR	This individual does not have such a nice physical appearance	☐	☐
5.	☐	☐	This individual doesn't do that well at paying jobs	OR	This individual does do well at paying jobs	☐	☐
6.	☐	☐	This individual is liked by those he/she is romantically interested in	OR	This individual is not that well liked by those he/she is interested in	☐	☐
7.	☐	☐	This individual often doesn't do the right thing	OR	This individual usually does do the right thing	☐	☐
8.	☐	☐	This individual is able to make close friends	ORT	This individual finds it hard to make really close friends	☐	☐
9.	☐	☐	This individual does well at schoolwork	OR	This individual doesn't do that well at schoolwork	☐	☐
10.	☐	☐	This individual is popular	OR	This individual is not that popular	☐	☐
11.	☐	☐	This individual is not that athletic	OR	This individual is athletic	☐	☐
12.	☐	☐	This individual is good-looking	OR	This individual is not that goodlooking	☐	☐
13.	☐	☐	This individual does his/her best on paying jobs	OR	This individual does not always do his/her best on paying jobs	☐	☐
14.	☐	☐	This individual is not dating someone he/she is romantically interested in	OR	This individual is dating someone he/she is romantically interested in	☐	☐
15.	☐	☐	This individual usually acts the way he/she is supposed to	OR	This individual often doesn't act the way he/she is supposed to	☐	☐
16.	☐	☐	This individual doesn't have a close friend he/she can really trust	OR	This individual does have a close friend he/she can really trust	☐	☐

13.6.5 **Scoring template for SPPC**

SCORING KEY

SELF-PERCEPTION PROFILE FOR CHILDREN
(Revision of the Perceived Competence Scale for Children

Susan Harter, Ph.D., University of Denver, 1985

1.	4	3	Some kids feel that they are very *good* at their school work	**BUT**	Other kids *worry* about whether they can do the school work assigned to them.	2	1
2.	1	2	Some kids find it *hard* to make friends	**BUT**	Other kids find it's pretty *easy* to make friends.	3	4
3.	4	3	Some kids do very *well* at all kinds of sports	**BUT**	Other kids *don't* feel that they are very good when it comes to sports.	2	1
4.	4	3	Some kids are *happy* with the way they look	**BUT**	Other kids are *not* happy with the way they look.	2	1
5.	1	2	Some kids often do *not* like the way they *behave*	**BUT**	Other kids usually *like* the way they behave.	3	4
6.	1	2	Some kids are often *unhappy* with themselves	**BUT**	Other kids are pretty *pleased* with themselves.	3	4
7.	4	3	Some kids feel like they are *just as smart* as as other kids their age	**BUT**	Other kids aren't so sure and *wonder* if they are as smart.	2	1
8.	4	3	Some kids have *alot* of friends	**BUT**	Other kids *don't* have very many friends.	2	1

13.7 Appendix 7: SDQ self-report

Strengths and Difficulties Questionnaire

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of how things have been for you over the last six months.

Your Name ..... Male/Female

Date of Birth.....

	Not True	Somewhat True	Certainly True
I try to be nice to other people. I care about their feelings	☐	☐	☐
I am restless, I cannot stay still for long	☐	☐	☐
I get a lot of headaches, stomach-aches or sickness	☐	☐	☐
I usually share with others (food, games, pens etc.)	☐	☐	☐
I get very angry and often lose my temper	☐	☐	☐
I am usually on my own. I generally play alone or keep to myself	☐	☐	☐
I usually do as I am told	☐	☐	☐
I worry a lot	☐	☐	☐
I am helpful if someone is hurt, upset or feeling ill	☐	☐	☐
I am constantly fidgeting or squirming	☐	☐	☐
I have one good friend or more	☐	☐	☐
I fight a lot. I can make other people do what I want	☐	☐	☐
I am often unhappy, down-hearted or tearful	☐	☐	☐
Other people my age generally like me	☐	☐	☐
I am easily distracted, I find it difficult to concentrate	☐	☐	☐
I am nervous in new situations. I easily lose confidence	☐	☐	☐
I am kind to younger children	☐	☐	☐
I am often accused of lying or cheating	☐	☐	☐
Other children or young people pick on me or bully me	☐	☐	☐
I often volunteer to help others (parents, teachers, children)	☐	☐	☐
I think before I do things	☐	☐	☐
I take things that are not mine from home, school or elsewhere	☐	☐	☐
I get on better with adults than with people my own age	☐	☐	☐
I have many fears, I am easily scared	☐	☐	☐
I finish the work I'm doing. My attention is good	☐	☐	☐

Your signature ..... Today's date .....

Thank you very much for your help

13.8 Appendix 8: Self-Understanding Interview Schedule

Self-Understanding Interview - Damon & Hart 1988

Item 1: Self-definition.
What are you like? What kind of person are you? What are you not like?

Probes – What does that say about you? Why is that important? What difference does that (characteristic) make? What would be the difference if you were (were not) like that?

Item 2: Self-evaluation.
What are you especially proud of about yourself? What do you like most about yourself? What are you not proud of? What do you like least about yourself?

Probes – What does that say about you? Why is that important? What difference does that make?

Item 3: Self in past and future
Do you think you'll be the same or different 5 years from now? How about when you're an adult? How about 5 years ago? How about when you were a baby?

Probes – What will be the same? What will be different? Why is that important?

Item 4: Self-interest
What do you want to be like? What kind of person do you want to be? What do you hope for in life? If you could have three wishes, what would they be? What do you think is good for you?

Probes – Why do you want to (be that way, have those things you hope for, have those wishes)? What else do you (hope for, wish for, believe is good for you)? Why is that good for you?

Item 5: Continuity
Do you change at all from year to year? How (how not)? If you do change from year to year, how do you know that it's still always you?

Probes – In what ways do you stay the same? Is that an important thing to say about you? Why?

Item 6: Agency

How did you get to be the way you are? How did that make you the kind of person you are now? How could you become different?

Probes – What difference did that make? Is that the only reason you turned out like you did? Is that the only reason? What else could make you different? How would that work?

Item 7: Distinctness

Do you think there is anyone who is exactly like you? What makes you different from anyone else you know?

Probes – Why is that important? What difference does that make? In what other ways are you different? Are you completely different or just partly different? How do you know? Are you different from everybody or just some people? How can you be sure that you're different from everybody else even when there are many people in the world that you don't know?

13.9 Appendix 9: KIC interview schedule

Subject Number: _____ Date: _____ Time: 1 / 2

KNOWLEDGE INTERVIEW – CHILD (KIC)

1. Now I'm going to ask you some questions about your accident.
So what can you tell me about your accident?
(if you can't remember then has anyone told you anything about what happened? What happened then? Probe about being taken to hospital – knowledge of any hospital procedures undertaken, which hospital, how long there. Do you know why you had to go to hospital? Physical injuries?)

2. Has anyone ever told you that you had a head injury?
Do you know what that is?
(Do you know anything else about it?)

3. Knowledge of brain functioning.
Do you know anything about the brain. Do you know what the brain does?
(Probe about what functions it controls, where it is in the body, what does it look like, do you know what it is made of).

4. Do you know what can happen to the brain if you have an accident?

5. Have you heard of the word coma? What is it?

6. Were you in coma? For how long?

KNOWLEDGE OF LONG TERM EFFECTS

7. Do you know if people usually have problems after having an accident when they have hit their head?

(Do you think they might have problems with thinking? Physical problems?)

8. Child's specific deficits.
How about you, do you have any problems since your accident?

Now I'm going to list some of the problems people say thay have – I want you to tell me if any of these are true for you.
Concentrating
Getting tired easily
Remembering things

Keeping up with the rest of the class
Planning things, getting organised
Walking problems
Writing problems
Speaking or talking
Saying sentences so they make sense
Understanding what other people say (comprehension)
Reading
Feelings and behaviour: sad, tired, stressed, frustrated, difficulties at school

What things do you like doing? What things are you good at?

9. Ideas of normality

Do you feel like you are different from other people?

How are you different?

How are you the same?

13.10 Appendix 10: Sample of Children's Cooking Task instructions

CHOCOLATE CAKE

What you need

1 cup of sugar

3 eggs

½ (half) cup of powder chocolate

½ (half) tablespoon (tbs) of baking powder

½ (half) cup of flower

Butter to grease the pan

½ (half) cup of oil

The recipe

1	Ask an adult to turn on the oven to 210°.	
2	Break the eggs in a mixing bowl.	

13.11 Appendix 11: Executive Function Map sample

GOAL

Cooking task

PLAN

Cookery book

PREDICTION

How well will I do? How much will I get done?

Physical difficulties? Cognitive/thinking difficulties?

Self-rating:

1 2 3 4 5 6 7 8 9 10

DO

REVIEW

How did I do? Physical difficulties? Cognitive/thinking difficulties?

Self-rating:

1 2 3 4 5 6 7 8 9 10

Other rating (teacher, therapist, peer, family member)

1 2 3 4 5 6 7 8 9 10

13.12 Appendix 12: Approval letter from ethics committee

NHS
Health Research Authority

NRES Committee London - Fulham
Charing Cross Hospital
Room 4W/12, 4th Floor
Charing Cross Hospital
Fulham Palace Road
London
W6 8RF

Telephone: 020 331 17282
Facsimile:

24 February 2012

Mrs Lorna Wales
The Children's Trust, Tadworth
Tadworth,
Surrey
KT20 5RU

Dear Mrs Wales

Study title: **An exploration of the effect of a traumatic brain injury on the development of self-awareness in childhood**
REC reference: **11/LO/1833**

Thank you for your letter of 10 January 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

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Mrs Lorna Wales

Letter sent as PDF via email:
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April 29, 2014

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isbn: 978-1-4625-0297-4 author: Susan harter author_yesno: no chapter: chapters 2 and 3 figures:

2.1 and 3.1 pagenum: 28 and 74 pubyear: 2012

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am really keen to use them as single images and I wonder if you could help with this? Many thanks, Lorna
From: Gogtay, Nitin (NIH/NIMH) [E] [mailto:gogtayn@mail.nih.gov] Sent: Tue 21/09/2010 12:34 To: Wales, Lorna Subject: Re: brain maturation slides I am currently traveling out of the country and will return Oct 1st...will be happy to help out with the images if you send a reminder then? Thank you for your interst in out work...best, NG

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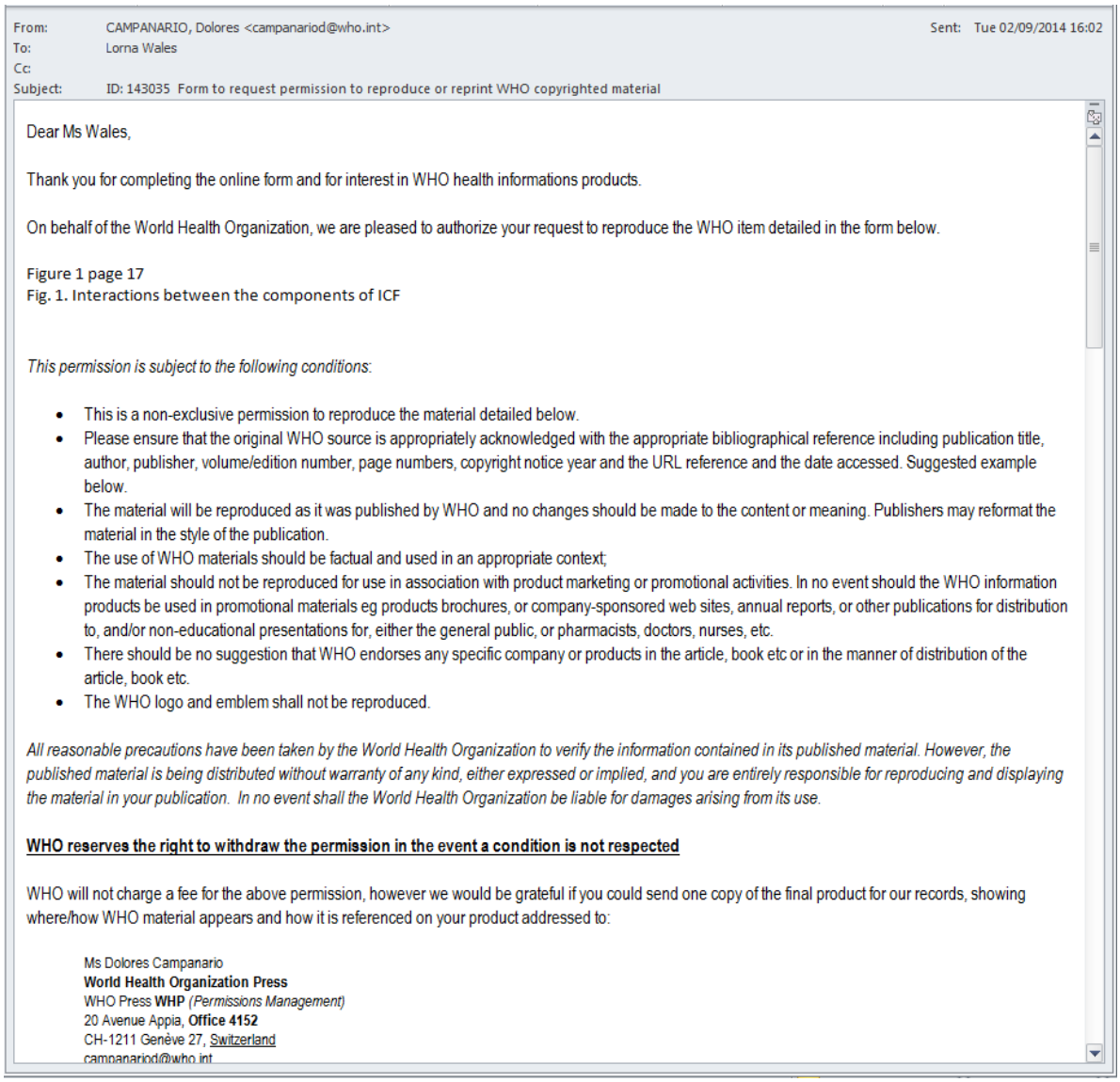

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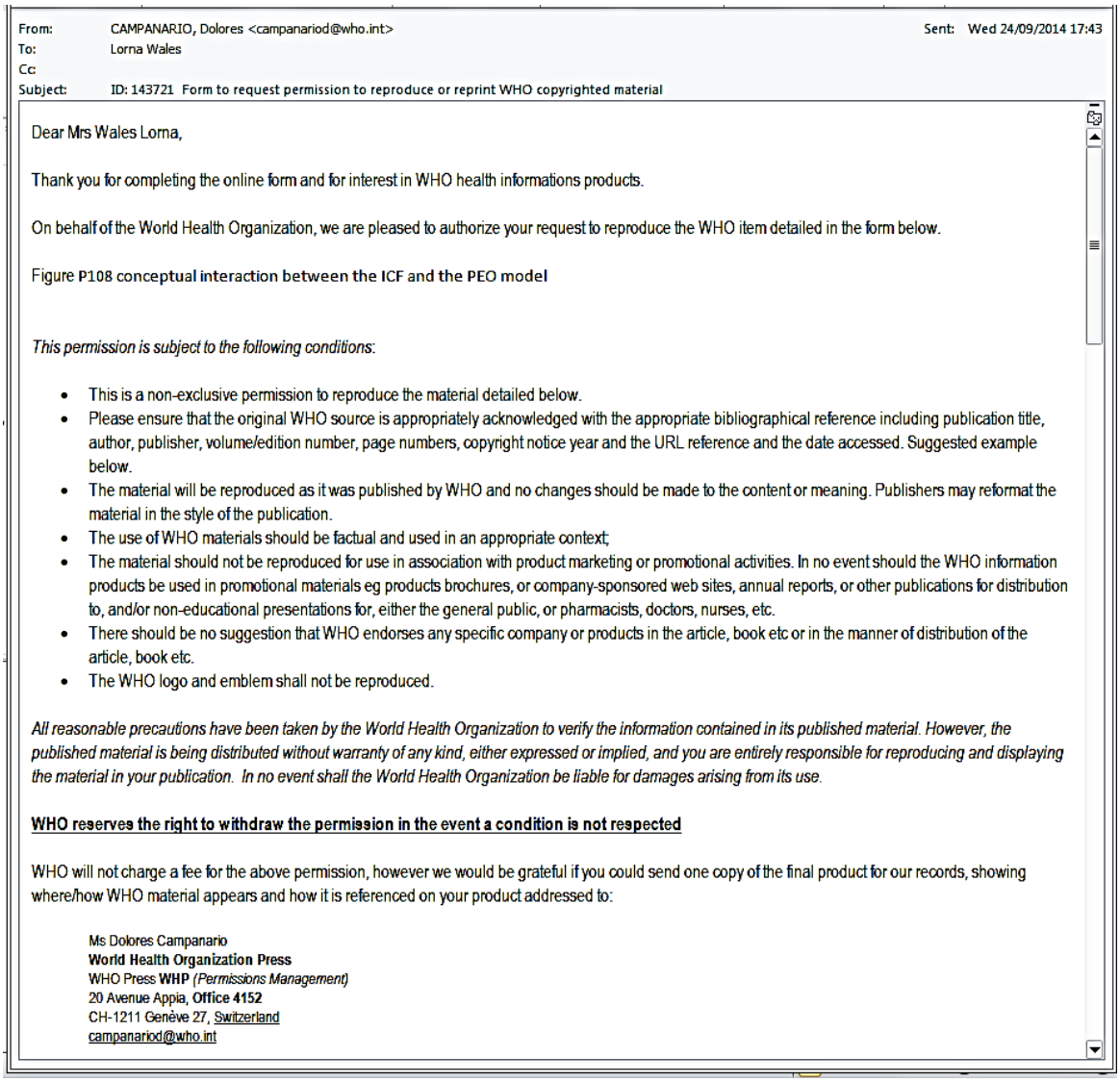

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Van: Lorna Wales [mailto:lwales@thechildrenstrust.org.uk]
Verzonden: dinsdag 3 november 2015 15:00
Aan: Carry Koolbergen <C.Koolbergen@iospress.nl>
Onderwerp: RE: permission to reproduce

Dear Carry

Thank you for your prompt reply. The illustration that I would like to use is:

Fig 1 A proposed model of awareness
Journal NeuroRehabilitation
Issue 15 (2000)
Title Understanding awareness deficits following brain injury
Authors Joan Toglia and Ursula Kirk
Page 60